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THE UNIVERSITY OF ALBERTA

HOME HEMODIALYSIS: THE EXPERIENCE OF THE SPOUSE AS THE DESIGNATED HELPER

by

Dawn Friesen

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES

AND RESEARCH IN PARTIAL FULFILMENT

OF THE REQUIREMENTS FOR THE

DEGREE OF MASTER OF NURSING

FACULTY OF NURSING

EDMONTON, ALBERTA

FALL, 1988

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ISBN 0-315-45578-0

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DEGREE: Master of Nursing

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled "Home Hemodialysis: The Experience of the Spouse as the Designated Helper" submitted by Dawn Friesen in partial fulfilment of the requirement for the degree of Master of Nursing.

(Supervisor)

Date: September 6, 1988

Dedication

This thesis is dedicated to two very special people in my life - Erwin and Jay.

To Erwin, for his loving help and support throughout my graduate studies and for his assistance in editing all drafts of this thesis.

To Jay, for all his "vim and vigor" and welcome hugs - such sweet diversion.

Abstract

Dramatic medical advances in the past twenty-five years have changed the lives of patients with end stage renal disease (ESRD) and their families. One of these advances has been home hemodialysis. Home hemodialysis follows the present trend in Canada which encourages people to accept the management and responsibility for their own health at home. The purpose of this study was to gather and evaluate data about the experience and perceptions of spouses who assisted with home hemodialysis of their partner.

A qualitative method was used to conduct this study. Grounded Theory technique was followed to develop a theory relevant to spouses of home hemodialysis patients. Data were collected by means of tape recordings of unstructured interviews.

A core category, the level of involvement of the spouses, clearly delineated three distinct spousal groups based on the duties they assumed during dialysis treatment and their day-to-day involvement in their partner's kidney disease management. The three groups have been labelled the do-ers, the minimal assistants and the joint partners. Another category, "level of resentment," was related to the emotional impact of assisting with home hemodialysis. These two categories were used to develop a model to explain variability between spousal groups.

The do-ers had high levels of involvement and resentment. Their over-involved role in dialysis made these spouses feel burdened. The minimal assistants had the least amount of involvement and expressed the strongest feelings of resentment. Their resentment resulted from imposed lifestyle changes exacted by ESRD. The joint partners were cooperatively involved with dialysis and expressed little resentment. These spouses shared tasks of home hemodialysis with their partners. Two broad themes relating to the marital relationship and the spouse's perceived degree of "normalcy" in their life also differentiated these spouses.

The findings in this study have implications for nursing families of patients with ESRD. The spouse who assists with home hemodialysis could benefit from ongoing support of their situation by nurses. In addition, periods of respite could be beneficial. Suggestions for further research include empirical extensions of the present study and longitudinal studies of spouses to understand the process of adaptation.

Acknowledgements

I am grateful to Dr. Marilyn Wood, my thesis committee chairperson, for her encouragement and support throughout this research.

A special thank you to Dr. Janice Morse for the introduction to qualitative methods of research, and for her ongoing enthusiasm and guidance in helping me do grounded theory.

Thank you to Dr. John Dossetor for his support through the research process and for his genuine interest in nursing.

I acknowledge the Alberta Foundation for Nursing Research, the Alberta Association of Registered Nurses and the Kidney Foundation of Canada for financial support of this research.

To my parents and family who have always believed in me.

To two very special friends and colleagues who have been supportive throughout my studies, and particularly in my accomplishment of this thesis. Thanks for helping me keep things in perspective - Ann Tourangeau and Maureen McQueen.

And finally, to the spouses who so generously gave of themselves and shared so much of their lives to make this research possible.

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Chapter I: Introduction

Statement of the Problem

Dramatic advances in medical technology in the past twenty-five years have changed the lives of patients with end stage renal disease (ESRD) and their families (Palmer, Canzona & Wai, 1984; and Plough, 1986). Hemodialysis has gained acceptance as the treatment of choice for ESRD (Eddins, 1985). Technological advances have made it possible for some patients to receive hemodialysis at home as an alternative to treatments in the hospital setting. Home hemodialysis follows the present trend in Canada which encourages Canadians to accept responsibility for their own health and to manage their health problems at home. Although home dialysis is less expensive than in-center hemodialysis in terms of direct costs to the health care system (Blagg, Hickman, Eschbach & Scribner, 1970; Eddins, 1985; Palmer et al., 1984; Plough, 1986; and Strauss, 1986), social costs to the patient and family may be high (MacElveen, 1972; Stark, 1985; and Walters, 1985). Most of the research on adaptation to hemodialysis has focused on the patient (Buck, Roy, and Atcherson, 1986; Reichsman & Levy, 1972; and Stark, 1985) but the spouse who assists with the treatment, and lives with the patient, experiences potential losses and changes too. Role relationships, family dynamics, life-style and economics must accommodate the changes in the patient - for the rest of the patient's life

(Dimond, 1979; Kossoris, 1970; Schreiber & Huber, 1985; Shambaugh & Kanter, 1969; Shambaugh, Hampers, Bailey, Snyer & Merrill, 1967; Smith, Curtis, McDonald & DeWardener, 1969; and Steidl, Finkelstein, Wexler, Feigenbaum, Kitsen, Kliger & Quinlan, 1980; and Streltzer, Finkelstein, Feigenbaum, Kitsen & Cohn, 1976). In order to prepare spouses to assist with home hemodialysis and to live with it successfully, the health care team must know and understand what it is like to be the spouse of a home hemodialysis patient. Yet, little is recorded in the literature concerning what it is like for the spouse who is actively involved with home hemodialysis. At present, it is not really known how spouses adjust to living in this situation, what factors are perceived as important to them, nor what influences their adjustment. The nurse is a central figure in the multi-disciplinary team that prepares and supports people involved with home hemodialysis. Without knowledge and understanding of the situation nurses may not be able to effectively promote adaptation to home hemodialysis.

Purpose

There were two major purposes for this study. The first purpose of this qualitative research study was to elucidate issues and variables of interest pertinent to spouses who are the designated helpers of home hemodialysis patients. Factor-isolating was used to describe concepts and factor-relating

was used to develop a theory (Diers, 1979; and Field & Morse, 1985) important to the spouses of home hemodialysis patients.

Research Questions

The following questions guided the research:

1. What is the experience of being the spouse of a home hemodialysis patient?
2. How does the spouse describe the experience of being the designated helper for hemodialysis?
3. How does the spouse describe the day-to-day reality of living with a partner on home hemodialysis?
4. What factors appear to influence the spouse's response to living with a home hemodialysis partner?

Definition of Terms

The following definitions were used in this study:

Home Hemodialysis - the procedure of hemodialysis on a day-to-day basis in the home setting when the partner and the spouse have received appropriate training.

Partner - the person undergoing dialysis treatment for kidney disease.

Spouse - the person who is married to or in a common-law relationship with, and residing with the partner receiving dialysis, and who is the designated helper for the dialysis treatment.

Chapter II: Survey of the Literature

Review of the literature was extended to include some of the early research on Hemodialysis. Several of these original research studies (Czaczkes & De-Nour, 1978; Shambaugh et al., 1967; Shambaugh & Kanter, 1969; and Smith et al., 1969;) are pervasive in the literature and were relevant to the current situation of home hemodialysis.

Each of the following themes was reviewed; coping with ESRD as a chronic illness, stress in home hemodialysis, social support and role functioning in home hemodialysis.

Coping

The patient's family is acknowledged to be important in the patient's response to chronic illness (Dimond & Jones, 1983; Moos, 1984; Strauss, 1975; and Strauss, 1986). Strauss (1986) suggests that coping with chronic illness can be an immense strain on marital relationships and that the burden imposed on the spouse can be enormous. Strauss' research has focused on patient care and illness management and he is only recently beginning to look specifically at spouses.

The studies in this category are characterized by a perspective which emphasizes patient adaptation to dialysis (Brand & Komorita, 1966; Buchanan & Abram, 1976; Dimond, 1979; Jones and Preuett, 1986; Levy, 1974; Rapaport, 1973; Reichsman & Levy, 1972; and Stark, 1985). Demographic characteristics such as age, sex,

level of education and income are most frequently examined as they relate to coping. Coping has been measured in a variety of ways including return to previous employment, stability of physical status and number of medical complications secondary to hemodialysis.

The multi-factorial nature of illness takes into account social factors that are related to coping. The patient's family is identified as part of the human environment that contributes significantly to the meaning of illness (Feldman, 1974; Jones & Preuett, 1986; and Moos, 1984) and management of that illness (Holcomb & MacDonald, 1973; MacElveen, 1972; Moos, 1984; and Strauss, 1975). While it has been established that the social environment is important, very little research has been done that describes the characteristics on coping capabilities of the people that make up the social environment for the patient.

Some research has been done that examines family coping with hemodialysis (Dimond, 1979; and Palmer et al., 1984). It is of interest to note that few studies deal directly with the spouse of the dialysis patient, especially as the spouse is so intimately involved and in home hemodialysis is at least partially responsible for the patient's treatment. Shambaugh and Kanter's (1969) group work with the spouses of dialysis patients was done in the early days of dialysis and was based on psychoanalytic theory. Recently, Srivastava (1987) examined coping strategies

used by spouses of patients on continuous ambulatory peritoneal dialysis (CAPD). Data were collected from an etic-perspective by means of a semi-structured interview and self-assessment of coping using a visual analogue scale.

In a study reported in 1983, Schoeneman and Reznikoff undertook to identify systematically those spouses of home hemodialysis patients who were at risk for experiencing difficulties in coping with the home dialysis treatment and the illness in their partner. In addition, they investigated select personality variables related to the spouse's ability to live with the stress of living with chronic illness. This study looked specifically at the relationship between locus of control orientation and adjustment for spouses of home dialysis patients using quantitative research methods. The results of this study are of limited clinical usefulness in predicting spousal adaptation to home hemodialysis since their focus was so specific and the results were not conclusive. No differences were found in level of adjustment between locus of control by others or belief in control by chance or between external health locus of control. The authors attributed lack of significance in findings to problems inherent in test instruments. While such research can provide information to nurses, the picture of spousal response to dialysis remains sketchy. Notably, no research studies were found

that examined the spouse's perception of coping with home hemodialysis.

Stress in Home Hemodialysis

In addition to the many stressors associated with any chronic disease (Dimond & Jones, 1983; Moos, 1984; and Strauss, 1986) and ESRD in particular (Czaczkes & De-Nour, 1978; and Richard, 1986), home hemodialysis imposes the added stressor of responsibility for treatment using a highly technical procedure that can prolong life or cause death if malfunctioning (Esmond, Strauch, Zapata & Hernandez, 1967). Several other articles on the stress of home hemodialysis are from the patient's perspective (Beard, 1969; Blagg et al., 1970; Buck et al., 1986; Eddins, 1985; Hansen, 1972; and Schreiber & Huber, 1985). It is suggested in the literature that stressors identified by patients may be similar to those of their spouse, however, this has not been investigated.

Four articles discuss stresses on the spouse involved with home hemodialysis (Hampers & Merrill, 1966; Schreiber & Huber, 1985; Shambaugh & Kanter, 1969; Smith et al., 1969) all from a medical perspective. It must be noted that three of these studies were conducted when home hemodialysis was first introduced and may not represent the present situation. Findings from these early studies suggest that psychopathological reactions to the stress of home hemodialysis are very high in spouses, with up to 60% experiencing depression and 25% requiring psychiatric treatment.

A study by Holcomb and MacDonald (1973) found that 87% of the spouses reported enjoying family life, but the same group also had adverse reactions to stress. These findings appear to be contradictory. Schreiber and Huber (1985) concluded that psychological stress is greater for spouses of in-center dialysis patients than for spouses of home hemodialysis patients but offered no explanation to account for the differences.

The literature is conclusive that home hemodialysis is stressful for the spouse. In addition, early studies indicate psychopathological reactions to stress. However, case studies (Hampers & Merrill, 1966), treatment program reviews (Shambaugh & Kanter, 1969; and Smith et al., 1969) and questionnaires (Schreiber & Huber, 1985) do not provide an indepth analysis. No statistical tests of significance or control groups were used. No attempt was made to examine the spouses own perceptions of the situation. Overall, the stress literature demonstrated the use of unsophisticated methods and a predominantly medical orientation. Questions related to the variables affecting spousal responses were not clearly addressed.

Social Support

Social support is a major factor in adaptation to stressful life events (Dimond, 1979; Dimond, 1980; Dimond & Jones, 1983a; Dimond & Jones, 1983b; Hilbert, 1985; Norbeck, 1981; and Waltz, 1986). Dimond and Jones (1983b) state that social support

involves communication of positive affect, social integration, instrumental behavior and reciprocity in interactions.

Social support for ESRD patients has been examined (Dimond, 1979; Dimond, 1980; Hart, Tanenbaum & Thompson, 1985; Hilbert, 1985; and Steidl et al., 1980). Spousal support was associated positively with morale (Dimond, 1980; MacElveen, 1972; and Steidl et al., 1980), compliance to medical regimen (Dimond, 1980; Hilbert, 1985; MacElveen, 1972; and Steidl et al., 1980) and total activity of the dialysis patient (MacElveen, 1972). MacElveen, Hoover and Alexander (1975) conducted a study to measure patient outcome success related to cooperation among the patient, spouse and physician. The findings showed that positive support and a greater degree of cooperation between the dialysis partner and the spouse resulted in closer adherence to the medical regimen, higher patient physical status and higher patient morale. The study showed that spousal support was helpful for the patient but there was no mention of the effect on the spouse.

The presence of a supportive spouse appears to buffer stress for the patient. But, how does this affect the spouse? On the assumption that spouses experience stress associated with home hemodialysis and sharing the life of the patient, it would seem realistic that the supporting spouses would themselves need a social support system. Research on spouses of patients with COPD (Sexton & Munro, 1985) and myocardial infarction (Bramwell, 1986;

and Waltz, 1986) identify social support as an adjustment factor. Conley, Burton, De-Nour (1981) conducted a study to examine support systems for both patients and spouses on home dialysis. Findings about the spouses revealed that their support systems were rated lower than patients both on satisfaction and frequency. In addition, spouses reported feeling less supported by household members. Reported lack of social support for spouses may be a factor in their adjustment to home hemodialysis. Since little research geared to the specific needs of spouses of home hemodialysis patients has been done, there is no background information to warrant an intensive investigation of social support for these spouses.

Role Functioning

Home hemodialysis is a challenging prolongation of life and requires the presence of an intensely involved partner to assist with the treatment procedure (MacElveen, 1972). Generally, the studies show that there is role reversal as the patient assumes a dependent role and this requires adjustment by both partners (Bailey, Mocelin, Hampers & Merrill, 1972; Hampers, Schupak, Lowrie & Lazarus, 1973; Klein, Dean, & Bogdonoff, 1967; Kossoris, 1970; Palmer et al., 1984; and Stapleton, 1983). The studies done have variability in their focus and include: the impact of role changes on the patient (Bailey et al, 1972; and Stapleton, 1983); role changes related to coping with stress (Kossoris, 1970); role

changes in the context of the total family (Palmer et al., 1984); and roles defined by patterns of psychologic reaction (Bailey et al., 1972; and Klein et al, 1967). None of these studies investigated the spouses' perceptions of roles.

Marital roles and relationships may influence, or be influenced by, roles taken in home hemodialysis. Brackney (1979) conducted a study to examine the impact of home hemodialysis on the marital dyad to determine how the interaction between the marital partners affected their marital satisfaction and performance of dialysis-related tasks. The data suggested that the patient's medical adaptation was enhanced when there was a non-conflictual relationship and when the spouse made a positive emotional adjustment. The spouses were interviewed for their perceptions of the marital relationship and emotional responses to home dialysis. Raters scored the interviews for twenty pre-selected variable. The spouses also completed the Locke Wallace Marital Adjustment Scale. In addition, nurses rated emotional adaptation of spouses and their functioning during hemodialysis. While this study shed light on the spouses as helpers, a truly emic perspective was not obtained and quantifying pre-selected variables may have missed important variables that only the spouses could identify.

In a comprehensive review of the literature related to the family as a basic unit in health care, Litman (1974) discussed the

concept of family roles relative to illness. While outdated as a review of the literature, it is interesting to note two of Litman's suggested areas for further research:

- The impact of illness on specific role relationships among family members.
- The pressures placed on the family and its members in serving as a non-institutional source of care.

Since Litman's 1974 article, two studies were found that examined the spouse's role in home hemodialysis (Streltzer et al., 1976 and Peterson, 1985). Based on case studies of six couples, Streltzer et al. (1976) commented that the role of the spouse is crucial in the process and outcome of home hemodialysis. Unfortunately, this study was limited mainly to the functional and financial aspects of the spouse role. It was found that for the spouse home hemodialysis brings several disadvantages: less free time, decreased mobility and increased responsibility. Streltzer et al. recommends that home hemodialysis training programs place a major emphasis on the spouse and that support be offered to the spouse. Peterson (1985) studied nineteen women who assisted their husbands with home hemodialysis to explore the impact on the spouses who assume the helper role in dialysis. Data were gathered through telephone interviews with the spouses, a staff rating scale of the spouse's psychosocial adjustment and an adapted variation of the Sickness Impact Profile (SIP). The author noted that adaptations

of the SIP from its original form raised questions about the reliability and validity of the instrument. Dialysis staff rating scales for spousal psychosocial adjustment must also be carefully considered for accuracy relative to the spouses own perceptions of their psychosocial adjustment. The results from this study showed different patterns of adjustment that included no role disruptions, role continuity and flexibility, and role strain and role overload. Without knowledge and understanding of the spousal experience with home hemodialysis, counselling, support and preparation may be inadequate or ineffective.

Summary

The literature reviewed offers some insight into possible factors, and their relationships, related to the experience of home hemodialysis. However, most of the information is from an etic perspective and not focused specifically on the spouse. Because so little verified information is available about the spouse's experience, this study was conducted as an exploratory descriptive and factor-relating investigation of the phenomenon. By starting from an emic perspective, this study provides a valid foundation for future studies in the area.

Chapter III: Method

Introduction

The choice of method in a research investigation is determined by the research question being asked, the nature of the phenomenon being studied, the purpose of the study, the amount of pre-existing knowledge on the topic, and setting constraints (Bogdan & Biklen, 1982; Field & Morse, 1985; Knafl & Howard, 1984; Mead, 1976; and Reichardt & Cook, 1979). The purpose of this study was to gather and evaluate data about the experience and perceptions of spouses of home hemodialysis patients. Qualitative analysis is the most suitable method to examine questions dealing with subjective experience and perceptions, situational meaning, and areas where there is little pre-existing knowledge (Bogdan & Biklen, 1982; Chenitz & Swanson, 1986; Field & Morse, 1985; Morse, 1986; Reichardt & Cook, 1979). Therefore, a qualitative method was utilized for this study. Subjective information from the spouses' point of view (emic perspective) was necessary in order for the researcher to develop an understanding of these experiences.

Grounded Theory

The particular qualitative research approach used in this study was the "grounded theory approach" of Glaser and Strauss (1967, p.2) which is defined as "the discovery of theory from data systematically obtained from social research." The aim of

Grounded Theory is to develop a theoretical explanation which "fits" the area of inquiry, rather than verification of existing theory. Grounded Theory is a process of collecting data and systematically analyzing it by constant comparison, as it is coded, until a theory results. Glaser and Strauss (1967, p.45) use the term "theoretical sampling" to describe the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges.

This process results in a theory that works. Glaser and Strauss (1967, p.1) suggest that a Grounded Theory "provides us with relevant predictions, explanations, interpretations and applications."

The objective of Grounded Theory is to discover the emic perspective, that is, the lived experience of the participants in the situation, from their point of view. Therefore, Grounded Theory was particularly suited to the purpose of this study about the experience of spouses of home hemodialysis partners.

Levels of Theory

There are several ways of classifying theories (Field and Morse, 1985). Dickoff and James (1968) suggested the following four levels of theory development - factor-isolating, factor-relating, situation-relating and situation producing. Using

the method of Grounded Theory as outlined by Glaser and Strauss (1967) a theory evolves that is both factor-isolating and factor-relating. Factor-isolating, a descriptive theory, is the first level of theory development. The concepts and categories derived from using the Grounded Theory method are factor-isolating. The results of this study identified three distinctive categories of spouses of home hemodialysis partners. As noted by Field and Morse (1985, p.9) "factor-searching or naming studies are descriptive in nature and occur at the exploratory or formulative stage of theory development."

The process of Grounded Theory development extends beyond description of categories and concepts by making connections between them. Searching for relationships between already identified and described categories results in a theory that is factor-relating. Field and Morse (1985, p.10) suggest that "carefully designed research at the level of factor-searching and factor-relating will provide a sound descriptive base of nursing and nursing practice."

Data Collection Methods

The Sample. Since this study was concerned with meaning, and not with distribution or frequency, a non-probability sampling technique was used (Morse, 1986). Theoretical, or purposive, non-probability sampling was used (Field & Morse, 1985; and Morse, 1986). By this sampling method spouses of home hemodialysis

patients who were willing to talk about their experiences were chosen for the study. A complete list of spouses who assist with home hemodialysis was compiled by the host institution. All these spouses were sent letters by the nephrologists to briefly introduce the study and notify them that a nurse researcher may be contacting them. Of these twelve spouses, eight spouses were contacted by telephone by the researcher and they all agreed to participate. One spouse responded to the request to participate in the following way:

> "When I got that letter I read it over and I thought isn't this great. Someone is going to, that knows there is this other person in the background that is right in the same way of life, and somebody asks how they feel about it."

The spouses were all English speaking. They all resided in, or near, the city where the study was conducted. They ranged in age from thirty-three to sixty-six years. Three of these spouses did not work outside of the home, one was employed part-time and four spouses worked at full time employment. The educational level of the participants ranged from grade four to seven years of university. Seven of the participants were female. See Table 1 for a summary of demographic data of the sample.

The Site. With the exception of one interview, all interviews were conducted in the participants' homes. It was expected that the home environment would offer a more relaxed

Table 1

Demographic Data of Sample

Age	Sex	Years Married	Time on Home Dialysis (in months)	Number of Children Living at Home	Employment Status
66	F	36	96	0	Retired
57	F	30	96	0	Part-time
36	F	18	48	3	Full-time
44	F	16	11	0	Homemaker
58	F	38	18	0	Homemaker
55	M	27	15	0	Full-time
33	F	11	5	1	Full-time
34	F	16	36	2	Full-time

atmosphere for the interview and would better accommodate the participant in terms of time and travelling requirements. One interview was conducted in a private office at the participant's place of work.

The host institution was a large, urban hospital that had extensive nephrology services. The nephrology department includes a home hemodialysis training unit and support services for renal patients and their families.

Data Collection. Initially all potential participants were notified of the study by a letter from the nephrologists. Participants were contacted by telephone by the researcher to explain the study and seek their permission to participate. During the telephone conversation an interview was arranged. Data were collected by means of tape recordings of these interviews. The interview tapes were then transcribed. Five of the participants were interviewed twice, two were interviewed once and one participant was interviewed three times.

An unstructured interactive interview technique was used to collect data. At the interview the researcher presented as the learner and asked the "expert" participants to share thoughts and feelings about their experience as the spouse of a home hemodialysis partner. The unstructured interview facilitated the process of exploration (Strauss, 1986) and as noted in Chenitz and Swanson (1986, p.81) "the subjects guide you into their world, the

world that you, the researcher, need to enter and examine." Initially broad, open-ended questions were used to guide the interview. Later, as data were collected, interview questions became more focused and probed into topics that the participants identified as meaningful to them. By repeatedly questioning and testing developing concepts against emerging data the researcher was able to verify categories and patterns and thus reliability of the results was enhanced.

The interviews ranged from 30 to 90 minutes in length. The participants were very willing to share information with the researcher and talked uninterrupted for prolonged periods of time. Generally, the second interview did not yield new information from the participants, but it was an opportunity for the researcher to clarify any concerns from the first interview and to verify emerging concepts.

In addition to interview transcription data, the researcher kept some field notes and wrote memos. One participant kept some personal written notes which she shared with the researcher.

Data Analysis

The steps of Glaser and Strauss' (1967) Ground Theory technique were followed for data analysis in this study. Data analysis was ongoing with data collection. Coding of data from the verbatim transcripts was initially sorted into broad categories. As new data were collected, the categories were

revised and changed and new categories were developed and labelled. Data collection continued until the categories were saturated, that is, "until it [was] clear what further instances would be located in the category" (Glaser and Strauss, 1967, p.231). This process involved moving back and forth between inductive and deductive reasoning and from data collection to data analysis.

The constant comparative method (Glaser and Strauss, 1967) was used to make comparisons between all pieces of data. This method permitted the researcher to identify properties of the categories. Comparisons were made between interviews from all spouses to identify common or unique themes. A core category labelled "level of involvement" was identified. This core category served to explain rather than simply describe the data and accounted for the degree of variability among participants. Clustering and linkages showed relationships between categories. A theory was developed based on the relationship between the core category, level of involvement, and the level of resentment of spouses towards home hemodialysis. Once the theory was developed the literature was reviewed to assess the emergent theory with existing theories. In addition, more data were collected which helped to support the theory. A study participant validated the concepts of the theory. Nursing peers reviewed both the process and the content of the developed theory. This provided

preliminary testing of the theory. The theory was supported by those who reviewed it.

Reliability and Validity

The issues of reliability and validity are important in qualitative research. However, assessing reliability and validity of a descriptive study is different from conventional ways of assessing reliability and validity of a quantitative study. Several methodological means were used to increase the credibility of this study.

Field and Morse (1985, p.117) suggest factors that can affect reliability of a qualitative study. The researcher's status, sampling procedures, the social context and the conditions under which data were gathered are important to reliability of qualitative research. These factors were addressed in this study as outlined below.

In this study the researcher was introduced as a graduate nursing student at the University to the participants by a letter from the nephrologists. This was followed up by a telephone call from the researcher. Additional information about the status of the researcher and the purpose of the study was provided. The participants were aware the researcher was a nurse which was conducive to data collection. As noted by Chenitz and Swanson (1985, p.85), "People identify nurses with a caring, nurturing role. Further, people will talk to nurses and reveal to them

content that they may not be so willing to disclose to others." The participants, however, also knew that the researcher was not a nurse associated with the home dialysis unit. This was important because spouses may have felt uncomfortable expressing their views freely to a nurse from the home unit. Spouses may have perceived their views as influencing their relationship with the home unit. One woman, who in the past had been both a home hemodialysis spousal assistant and a nephrology nurse, commented that non-association with the home unit was an important asset of the researcher and contributed to obtaining more personal and detailed data from the spouses.

The purposive sampling method used in this study was important in getting participants who were knowledgeable and involved in the area of inquiry. Only spouses who were currently assisting with home hemodialysis were participants. All the participants willingly agreed to be interviewed. The participants openly shared very personal aspects of their experience with home dialysis.

Interviews in the home were deemed to be appropriate for promoting a relaxed, non-formal atmosphere where the participants felt free to discuss their experience. Further, the setting offered the researcher an additional source of information about the home situation. The convenience of home interviews for the

participants contributed to their willingness and ability to participate in the study.

Field and Morse (1985, p.117) suggest that it is useful to verify data with information from several sources. This is inherent in the process of Grounded Theory. Data collected from one spouse were coded and then compared with coded data from other spouses. On subsequent interviews spouses were asked to clarify data from previous interviews and from data given by other participants. In this way commonalities and differences were made apparent.

Other methodological means were utilized to improve reliability of this study. The use of low-inference descriptors (verbatim accounts) provided by the participants, were used as raw data. Transcripts of recorded interviews were reviewed for accuracy prior to coding and analysis of data. In addition, excerpts from these transcripts have been included in the results to substantiate categories.

Participant review of data analysis is another way to ensure that the researcher views the data consistently with the participants. One of the study participants reviewed the proposed model at the end of the study. She was able to recognize her own placement in one of the three typologies. However, because she did not have any association with other home hemodialysis spouses she was unable to confirm the existence, or accuracy in

description, of the remaining two typologies. Further, she was able to confirm that the categories outlined in the study were topics of concern and interest to her as an assistant spouse for home hemodialysis.

Peer examination is also one way to question and verify the "discovered" theory. One peer was particularly helpful in assisting the researcher clarify and refine the emerging theory. This individual's perspective was unique and valuable to this particular research because she was both a nurse and had been a spouse assistant. The combination of her past experience of being a spousal assistant for home hemodialysis and her nursing knowledge and expertise were helpful in assessing the "fit" between the descriptive reality of the experience and the emerging theory as represented by the model. This woman agreed with the relationship between levels of involvement and resentment that resulted in the three typologies of spouses. Further to this, it was her opinion, based on years of working with nephrology patients and their families, that the model was representative of a larger population of spouses than the eight who were participants in this study. While generalizability is not the aim of qualitative research (Field and Morse, 1985, p.122) such support is indicative that the emergent theory meets criteria of Grounded Theory. Glaser (1978, p.6) wrote "Its [Grounded

Theory] generative nature always takes it [the theory] beyond the substantive area being studied."

Additional peer examination of the results and analysis included two experienced nurses from the home dialysis training unit. The nurses were able to verify the three typologies of spouses as represented by the model, based on their contact with many patients and their support of spouses in the training sessions for home hemodialysis. Furthermore, these nurses could offer no examples or cases of spouses who did not fit within the given typologies. As noted in Field and Morse (1985, p.121) "a constant search for negative instances of categories or disconfirming evidence for tentative constructs is critical both in ongoing and terminal analysis of data."

The emergent theory was presented to the participant and peers for two purposes. Firstly, their input served to further clarify concepts and refine the model. Secondly, it was a means of strengthening the credibility of the developed theory by obtaining confirming feedback about the model which represented the theory.

Risks and Benefits

All participants freely and willingly agreed to participate and signed a consent form (See Appendix A). The spouses had a clear understanding that they could terminate the interview at any time. All the interviews were conducted in an informal manner

however it was possible that the participants could have been placed at risk of personal anxiety or emotional trauma since the interviews included sensitive issues for the participants. One participant cried during the interview. This was a reasonable reaction to the topic of discussion. She was clam prior to the researcher leaving the interview. Other participants did not express any untoward anxious or emotional upset.

There were no tangible benefits for these spouses to participate in this study. However, several spouses expressed appreciation for having been given the opportunity to talk about their experience. Presentation of an "interested and listening ear" was seen to be a benefit for the participants.

Ethical Considerations

Ethical Approval. Ethical approval was granted by the Faculty of Nursing Ethics Review Committee at the University of Alberta. In addition, ethical approval was granted by the institution where these spouses' partners received nephrology care and where home hemodialysis training was given.

Anonymity. Several measures were undertaken to protect the identity of the participants. All the audio tapes were kept secured by the researcher and erased at the completion of the study. All participants were given a code number by the researcher to conceal their identity and protect their privacy. Only this code number appeared on the tapes and the transcripts.

In reporting the data, changes were made to characteristics that might have identified the participant. The interview transcripts, identified by code only, will be kept in a locked file by the researcher.

Chapter IV: Results and Discussion

Introduction

In this chapter the results of data analysis and the discussion will be presented. Using Grounded Theory methodology a core category emerged related to the level of involvement of the spouses with the home hemodialysis of the partners. As Glaser (1978, p.95) noted, a core category "indicates that it accounts for a large portion of the variation in a pattern of behavior." In this study, the level of involvement of the spouses clearly delineated three distinct spousal groups based on the duties they assumed during home hemodialysis treatment and their day-to-day involvement in other tasks of their partner's kidney disease management. The level of involvement has been applied to their actions or behavioral aspects of assisting with dialysis. The level of involvement was also reflective of their marital relationship and their emotional investment in dialysis.

Another major category emerged from the data related to the emotional impact of assisting with home hemodialysis. 'Resentment' was a term used by many of the participants in the study. The amount of resentment was related to the level of their involvement with home hemodialysis. The meaning of resentment in this study included any feelings of bitterness or discontent related to any aspect of management of home hemodialysis and the resultant effect on the couple's lifestyle. The level of the

spouses resentment also helped to differentiate between groups of spouses. The level of resentment was examined in terms of what aspects of home hemodialysis makes the spouses resentful and also what types of family arrangements lead to increased feelings of resentment.

Two main categories based on the spouses level of involvement and resentment were used to develop a model to explain the variability between spousal groups observed in this study. In combination, the two categories explain the variability between spouses and can account for similarities between and within groups. The two major categories were combined in a two by two matrix to form the model shown below.

Level of Resentment	Level of Involvement +	Level of Involvement −
+	A Do-ers	B Minimal Assistants
−	C Joint Partners	D

Figure 1

Model: Types of Spouses

The two by two matrix used as the model consists of relative levels of involvement and resentment. The study showed that there was neither total absence of resentment nor complete overwhelming resentment but rather a relative "more than" or "less than" degree of resentment. Similarly, the level of involvement did not indicate a total lack of involvement nor complete involvement but rather more or less involvement.

From this model, four types of spouses are differentiated. However, only three of these types cells A, B, and C were found in this study. Based on the descriptions of cells A, B, and C some speculative comments on cell D could be made.

Cell A spouses have been labelled the "do-ers." These spouses assumed nearly all the tasks of running home hemodialysis and therefore had a lot of involvement. They also expressed high feelings of resentment, generally about their "over-involved" role in dialysis which they found burdensome.

Cell B spouses have been labelled the "minimal assistants." These spouses had the least amount of actual involvement with running home hemodialysis and expressed the strongest feelings of resentment towards home hemodialysis. Their feelings of resentment did not flow directly from their duties with the dialysis treatment but rather from the imposed lifestyle changes exacted by home hemodialysis in particular, and their partner's kidney disease in general.

Cell C spouses have been labelled the "joint partners." In this group, the spouses and partners shared tasks involved with home hemodialysis. The reciprocity of duties in dialysis was reflective of the mutuality in their marital relationship. This group of spouses were least resentful of home hemodialysis and in fact, expressed positive feelings towards it.

Cell D spouses would have a low level of involvement, or no involvement at all, and would show very little resentment. There were no spouses in this study that fit into this group. It is speculated that partners of spouses in this group would run dialysis in the hospital dialysis unit. The lack of involvement in dialysis, particularly having it outside the home, would be reflected in the lesser degrees of resentment.

The remaining portion of this chapter has been divided into sections according to the three types of spouses - the do-ers, the minimal assistants and the joint partners. A descriptive analysis of the groups, including how the level of involvement is integrated with the level of resentment has been done. Following each result section the discussion of the results is presented. A final summary discussion of results concludes the chapter.

Grounded Theory method resulted in the emergence of the core category of "level of involvement" and the other major category of "level of resentment." In addition, other categories emerged from the data that provided information about similarities and

differences between the three groups and helped to further define the groups. These sub-categories were based on duties during hemodialysis, feelings about hemodialysis, spouse - partner relationships, interspousal communication, presence of the partner, protecting the partner, day-to-day management, support, and perspective on home hemodialysis and the future. The results are presented using these sub-categories within each typology.

The Do-ers

The spouses in this group were in their 40's and 50's with the average length of marriage 27 years. Two of these spouses were not employed outside the home and one was employed full time. None of these couples had children living at home.

Duties During Home Hemodialysis. In the home dialysis program both the partner and spouse are extensively trained in dialysis techniques. The patient is expected to assume responsibility for his/her own treatment at home. Although this is the philosophy of the home dialysis training unit, the reality of the situation as reported by these spouses is contrary to this philosophy.

The spouses in this group assumed nearly all aspects of running home hemodialysis. These spouses always remained near the dialysis machine for the duration of each treatment. These couples had the dialysis machine set up in, or adjacent to, the main living area. This arrangement permitted the spouse to "do

everything" required to run the dialysis and to complete other household tasks at the same time.

The active role of these spouses was characterized by such statements as:

> "I do everything. I put the needles in, I put in the local, I set it up. I have total involvement in the whole thing."
>
> "He depends on me for everything. Except needles, everything is my job."
>
> "I think because I took on the whole load to start with . . . I did everything the same as they would in a hospital. Complete. And now I get frustrated that I gotta do it all on my own . . . . If I don't do it, it doesn't get done."

These spouses were particularly task oriented when running dialysis, that is, they knew how to manage all the technical aspects of the machine. The spouses in this group "did" all the tasks while their partner assumed a relatively passive role in their own treatment. There was little sharing of these dialysis tasks. While on the dialysis run, the partners often requested things, such as a cup of tea or a change in the television channel that they could not get because they were connected to the machine. These jobs were named "go-for jobs" by the other groups of helper spouses. In this group of spouses these jobs were not seen as separate tasks independent of dialysis. Being responsible for nearly all the tasks of dialysis treatment, including

extraneous jobs such as removing the garbage and cleanup, providing emotional support for their partners and managing all the "normal" household tasks made these spouses feel overburdened. The burdensome nature of home dialysis created feelings of resentment.

Feelings About Home Hemodialysis. Spouses who assumed full responsibility for tasks involved with running dialysis expressed ambivalent feelings about it. They were happy to have their partner home and felt confident about their ability to carry out dialysis but at the same time they felt burdened and "tied-down."

These spouses said home dialysis was convenient because they could do other tasks at the same time they "did dialysis." It was also more convenient for the spouses than hemodialysis in the hospital because there are no travel time requirements, no wasted waiting time to be put on the machine and a much more flexible dialysis schedule. These spouses expressed positive feelings related to having the company of their partners while running dialysis. When these partners ran dialysis in the hospital, the spouses felt very lonely either at home or waiting in the hospital.

These spouses were confident in their ability to run dialysis. Positive experiences during the training session, familiarity with the treatment, past experience in coping with problems on the run, and complete involvement in all tasks

associated with dialysis promoted this confidence. These spouses felt well supported by the staff of the home dialysis unit for technical management and did not hesitate to call with questions or concerns.

"It doesn't intimidate me. It's normal."

The spouse's positive feelings of dialysis task proficiency were tempered by feelings that these circumstances were merely tolerable. These spouses talked about being "tied-down" with less opportunities or choices to do other activities. These couples did minimal travelling or socializing prior to dialysis and therefore dialysis did not create major changes in these activities. However, the fact that the choice to do these activities was now limited gave them a sense of loss of freedom.

> "Actually, when it comes right down to it, there's very little that changed for us. Our social life hasn't changed because we don't have much of a social life, so that [home hemodialysis] hasn't thrown a damper on it at all. We really never did anything different before in that respect. Again, the choice. Now there's certain evenings or one day out of the weekend we can't."

Other feelings that these spouses expressed included frustration about particular tasks such as ordering supplies and inserting needles. The "overwhelming" sense of never being finished with dialysis also contributed to this frustration. Some

days the spouses did not think beyond the end of the day because to think about doing this procedure forever, made the treatment seem even more burdensome.

The feelings of burden associated with the work of dialysis, lost opportunities or decreased choices, and general frustrations made these spouses feel resentful. These feelings of resentment were never explicitly directed towards their partners as individuals but rather towards the work they had to do and the lifestyle changes they had to deal with.

Relationship with Partner. This group of spouses had an average length of marriage of twenty-seven years. Roles and relationships were well established prior to initiation of home hemodialysis. The high level of spousal involvement resulted from previous role expectations of the spouse as the family caregiver. Dialysis was superimposed upon a relationship that had existing patterns of communication and ways of dealing with problems. One spouse in this group identified the existing relationship as being important to the overall adjustment to home dialysis.

> "I think it depends on the closeness you had with your spouse to start with, really. How well you work together, how well your communication was and how much time you did spend together."

A problematic area for this group of spouses was related to decreased sexuality in their marital relationship. All spouses in

this group expressed concerns about less physical intimacy in their marriages and the lack of any possible solution or lack of opportunity to express such feelings.

"I feel I'm treated more like a worker than a mate. There is no intimacy whatsoever, none."

"It has taken an awful lot out of our marriage - very hard to accept. I feel like I'm cheated. You have to learn to live with it. I don't think there are any options."

While the spouses attributed the decrease in sexuality to kidney disease, and not home hemodialysis, it was obviously an area of concern for them.

The increased length of marriage did not make adjustment to home hemodialysis less difficult or more successful for these spouses. Factors such as interspousal communication, protecting the partner and presence of the partner affected how home hemodialysis was incorporated into their lives.

Communication. These spouses perceived that communication with their partner was good.

"Our communication is fantastic."

"I never lie to my husband. The kids have problems, or the kids want money, I'll never give it, nothing without talking it over with him."

However, these spouses also told the researcher they were unable to share irritations, frustrations and feelings with their

partner. Communication lines were not as open as they perceived. These spouses thought that communicating their troubles might be helpful for themselves but harmful for their partners. As a result, they did not discuss their feelings about home hemodialysis with their partners.

> "I haven't discussed it [holidays] with my husband because I don't want him to feel, see it's bothering me."
>
> "This is different because it involves his health. So it's something that I won't outwardly get angry over."

These spouses would have been willing to receive counselling to help them deal with their problems but their partners refused. The spouses in this group contacted their social workers and found this helpful. The social workers offered an informal means of supportive counselling that did not require the cooperation of their partners.

Some communication patterns emerged from the data. One spouse developed pent up feelings of anger and frustration because she did not express her feelings and troubles to her partner. Another communication pattern included arguments with "screaming and hollering." Communication was ineffective however it did allow ventilation of the spouse's feelings. It is the researcher's impression that these communication patterns were "typical" of these relationships prior to dialysis and that home hemodialysis merely resulted in an extension of the use of these patterns.

Despite some difficulty with communication, these spouses were very supportive of their partners.

"For us it brought us very, very close together. We were close before but this was even another bind."

"We've always been very supportive of each other. In fact, when things are down more so than when things are good you almost could say."

These spouses had the view that even though they had some communication problems they had a strong, stable relationship with their partner that would endure despite home hemodialysis. Because of strong marital ties and personal support for their partner, resentment was focused on the tasks and not the person.

Presence of the Partner. A benefit of home hemodialysis is that the partner does not have to go to the hospital for dialysis. The presence of the partner during home hemodialysis was viewed as a positive aspect by this group of spouses.

"I got very lonely when he spent his time in the hospital and it was hard. It was so nice to have the machine at home and I could spend my time with him."

In this group of spouses, the presence of the partner was important to the spouse, for her own sake. As well, they were relieved of the responsibility of driving their partner to and from the hospital.

Protecting the Partner. One way that spouses helped support their partner was by trying to shield the partner from feelings or information that they believed would adversely affect the partner. These spouses expressed several ways in which they protected their partners.

"He quite often feels that he is a burden to me and I don't want to emphasize that so I feel I can't tell him everything that is bothering me because he has enough."

"I never talk to him about my illness."

In addition, they changed their lifestyle and habits to protect their spouses.

"I eat ahead of time. I don't like to eat in his presence - it just tempts him."

I love cold cuts but I just don't buy them because he can't eat them without getting sick."

By withholding more of their own concerns from their partners and taking on the burden of the dialysis treatment, these spouses believed they could lessen the burden on their partners. These spouses also made other lifestyle changes. One spouse realized that in her initial eagerness to help her partner she did everything. As time passed she found this role of "doing everything" increasingly difficult to deal with. She could not discuss it with her partner because "he already feels guilty."

This group of spouses expressed to the researcher the burden of home hemodialysis that they could not express to their partners.

"I shouldn't have taken on so much of the workload."

"I did everything the same as they would in hospital - complete. And now I get very frustrated that I gotta do it all on my own. I feel it's not fair, it's his body too. He should chip in just as much."

"It's to the point that if I don't do it, it doesn't get done."

"It's irritating. I just feel like I shouldn't have to take as much of the workload as I have."

These spouses assumed most of the actual work of dialysis because of role responsibilities in their marriage and to protect their partners. However, they had less opportunities for ventilation of feelings about the burden and therefore, expressed built up resentment about home hemodialysis.

Day-to-Day. The spouses in this group shared a great deal of information about the day-to-day management of home hemodialysis and other tasks not directly related to dialysis. These spouses did not work outside of the home. Involvement in managing the household and dialysis was their central focus. They expressed ambivalent feelings about their day-to-day life with a home hemodialysis partner. All these spouses said that very little had

changed in their life and that in fact, their life had remained relatively "normal."

"You work it in to make it a normal life."

"You have to make it part of your life. You can't lead a completely normal life and still be regularly going on the machine. You get very close to being normal - but not completely.

"This [home hemodialysis] was just a little extra that you have to change a little bit."

Underlying these general statements about the minimal amount of change imposed by home hemodialysis were more specific statements to suggest that indeed there were many changes that had occurred. Over a period of time these changes were incorporated into the day-to-day routine and they were no longer seen as changes from pre-dialysis days but rather had become the "normal."

Since these spouses did not work outside the home there was no impact of home hemodialysis in this area. One spouse commented that she might work but knew she could not cope with work and home hemodialysis.

"If I wanted to work full time I couldn't handle it. I cannot hold down a full-time job or it would be just too hard, it would not be worth it."

Their work as homemakers had not been significantly altered.

". . . very little of my work has changed except maybe I do more of the outside work."

Diet and fluid restrictions are part of the therapeutic regimen of a dialysis patient. The spouses in this group were particularly concerned about diet because the planning and preparation of meals, and the return to a "dry-weight" after dialysis was seen as their responsibility. Planning and preparing meals was a major concern and time commitment for the spouses.

"I watch pretty close on his diet 'cause I cook all the meals - no cold cuts or sauerkraut."

"Meals are a big part of his dialysis. I'm alot more aware of what he should have and what he shouldn't and the amounts of fluid that he should have."

These spouses discussed details about meal planning such as "soaking the potatoes" and special techniques they had devised for making the diet restrictions more palatable for the partner. While these spouses were actively involved in diet management for their partners they stressed that they "did" things but they did not say anything to encourage their partner to comply with the diet.

"I found myself once in awhile complaining you know 'you're taking in a little too much.' Not anymore. I haven't anymore."

"We go out to a wedding or a party, I see he's eating the wrong things but I say nothing. That's your life. So then he comes home, he's sick, he blames me for it."

Loss of sleep resulting in fatigue is known to be problematic for both dialysis patients and their spouses. The hours required to run hemodialysis three times per week are typically added on to a work day. Since neither of these spouses, and only one of the partners, had the added time pressure of a work commitment outside the home, lack of sleep seemed to be less of a problem for this group of spouses. One spouse noted that although they went to bed later, she slept better than when her partner went to the hospital for dialysis because she knew how the run went and she was more relaxed knowing he was not on the road travelling after a run. The spouses said they sometimes had less regular sleep because of dialysis but they could take daytime rests to compensate for any loss of sleep resulting from an early morning start or late night finish of a dialysis run. These spouses also commented that they sometimes lacked energy but this was not attributed to home hemodialysis.

"Everyone lacks energy some days."

The time required to run dialysis ranges from about fifteen hours to twenty-five hours per week. All spouses spoke about the impact of dialysis on their time but for this group of spouses

time was not a central element in accommodating home hemodialysis in their daily routine.

"It does cut into my time. Winter time it doesn't bother me because I'm not as busy. There's alot of things that I don't have to do, it can wait or it just doesn't have to be done. But summers, there's a lot of times in the evening I'd like to go out and cut the grass, I can't."

"It's a routine. It's not this rush, rush, rush."

These spouses had many years of experience in managing the household and the addition of home hemodialysis was not totally disruptive to the existing daily routine.

"It's just getting into a regular routine and to me it was getting back to when the kids were at home. Working it in and trying to stick to it . . . because you are tied up a certain amount of hours. Just scheduling yourself."

"You've got to be organized with your work. You've got to have your clothes washed, your meals made, and this was just a little extra that you have to change a little bit. But I was always organized with my work, all my life."

These spouses also commented on the flexibility in home dialysis times that was not possible when in the hospital. Although the spouse and partner could schedule the most convenient time to run dialysis, these couples tended to keep to an established routine with rare exceptions.

Socialization for these couples was decreased due to home hemodialysis. Poor health of their partner was seen to be the primary reason for less social outings.

"We stay home. He doesn't feel up to going."

"Sometimes you plan something and you can't go. He feels lousy so you do it tomorrow."

Both decreased free time and poor health of their partner contributed to less social activity. These spouses did not socialize on their own and therefore limitations of the partner were limitations on the spouse.

"I lost contact with friends of mine since hemodialysis and it was me that did it not them. They'd call and I'd be too busy and this sort of thing."

"We did spend all of our time together. We did absolutely everything together. He didn't go out with the boys and I didn't go out with the girls."

"You live so many years together and we enjoyed life when we were younger. We went, we did things together, dances and everything and now - 'bang' - this. But it's like I said, you have to give things up but I don't mind."

Spouses in this group expressed discontent about less opportunities for holidays. The circumstances faced by these couples, because of home hemodialysis, had reduced both their holiday time and options as to where they felt they could go.

"It seems like it's changed. More than likely I'll go and work and manage the shop and my husband will stay and do things around home, you know. It's just like you gotta plan things differently and it's just not the same."

For this couple, the husband got a holiday from his regular job. The spouse went to the shop and did her husband's job and still came home to assist with dialysis. Certainly there was a change in the daily routine but it was not a holiday for the spouse. This couple did not get time away from home together. For this spouse there was no break from being home and no break from running dialysis.

Another spouse saw possible opportunities for holidays but her partner was afraid to leave home.

"We could do more travelling, go on holidays but I think he's scared to go. He says in case I got sick there then what. So he just refuses, a flat 'no.' Now I'm trying to get him to get the motorhome and go to the lake for two weeks. Just to try it out and see if it would work. Maybe I could change his mind later because I'd really like to go."

Many aspects of day-to-day life for these spouses were altered by home hemodialysis. These spouses experienced the addition of many tasks related to dialysis as well as changes in time scheduling and routines, diet, sleep and rest, socialization, and holidays.

Support. To cope with day-to-day management of life in general, and home hemodialysis in particular, people need other people for help and support. It is reported in the literature that depression is common in spouses of dialysis patients. This group of spouses also reported feelings about being lonely and depressed. Spouses gave so much of themselves to support their partner but did not suggest that they received support from their partner. Even though they did not specifically say their partner was not supportive, they perceived that their strongest support came from outside the spousal relationship. Similarities within this group were striking. They said their children were supportive.

"My kids have been supportive. They always have been very supportive of anything that I've done anyways."

"If I didn't have the kids I don't know what I'd do."

The children in these families were adults and not living at home.

For these spouses the social worker associated with the home dialysis unit had helped give "mental support." One spouse identified lack of support as a "a source of frustration" but could not specify what kind of support she thought would be most helpful.

In keeping with their role as "do-ers" these spouses also found that activities or tasks helped them cope with a "down day."

"If I'm having a down day or just feeling a little lonely or depressed I get very frustrated and very angry with the machine. And I find then that I've got to go and do something I like doing to get myself out of that and not sit and brew about it."

"It's not easy but I'll just sit down and crochet."

Perspective. All the spouses expressed views on their outlook for the future related to living with a chronically ill partner. Characteristically, these spouses expressed mixed feelings and emotions. Similarly, their perspective on hemodialysis and the future was characterized by ambivalence. These spouses had partners who were not likely candidates for a kidney transplant. Dialysis treatment was seen as the only option for their partners. These spouses were resigned to this fact.

"No matter how I think, it's not going to change the facts."

"It isn't how a person would want to live but this is what happens - we just have no choice."

While these spouses saw home hemodialysis as the only treatment option for their partner they bolstered themselves by saying:

"It could be worse. I remind him of his brother growing up on crutches his whole life. Or I'll tell him about people that have no legs, no arms, can't hear, you know, and it

really helps me to think that way and I think it helps him when I remind him."

"It's never going to be great, even though it's alot better than the hospital unit."

These spouses were aware of their negative feelings and resentment of their lack of lifestyle choices and the burden of running dialysis. They verbalized them to the researcher. However, possibly as a means of coping, they tried to maintain an overall positive attitude to the situation they faced.

"I still wouldn't have it any other way. You know you have that bad with the good but the good outweighs the bad."

"It's great at home, much better than the hospital. We just have to do it, we have no other choice, that's our lives now."

Summary of Do-ers. The do-ers presented very set patterns of communicating and "ways of doing things" consistent with their long-standing roles and responsibilities in the marital relationship. These spouses had total involvement in the dialysis treatment. Their involvement extended beyond the treatment itself and included many aspects of day-to-day management of the treatment regimen including diet, rest and activity. While these spouses expressed some positive feelings about the convenience of home hemodialysis and their confidence in carrying out the procedure, they also expressed resentment towards home

hemodialysis. The negative feelings evolved from their level of involvement and included feelings of being over-burdened, tied-down and restricted in certain aspects of their lives. As well, feelings that this treatment was to be ongoing contributed to their feelings of resentment. The strong marital bond and emotional feelings towards their partners somewhat tempered the feelings of resentment experienced by these spouses.

Discussion. Living with end-stage renal disease, and home hemodialysis, is a challenge to patients and their spouses. The results of this study show that the spouse is affected by, and responds to, this challenge in several different ways. Spouses must learn to incorporate the treatment regimen, schedules, roles and responsibilities into their existing relationships and lifestyles. Many changes to their life are imposed by home hemodialysis.

The group of do-ers had traditional marital relationships with distinct husband-wife roles. Although the patients (husbands) had been taught to dialyze themselves and assume primary responsibility for their own treatment, these spouses quickly resumed pre-dialysis roles in incorporating home hemodialysis once the training period was over. In the traditional role of family caregiver these spouses assumed the added responsibility for complete dialysis care as an extension of the normal caregiver role. The responsibility for dialysis

required that the spouses did many extra tasks that were time and energy consuming. The feelings of "overwhelming" responsibility for the life, and possible death, of their husband and the burdensome nature of the treatment itself resulted in feelings of anxiety and resentment towards home hemodialysis. These results are similar to those of a study done by Whalen and Freeman, reported by Peterson (1985), who found stress and possible psychological problems for assistants were greatest when the assistant was required to carry primary responsibilities while the patient/partner assumed a more passive role. Schoeneman and Reznikoff (1983) suggested that the added stress of home hemodialysis as compared to hospital dialysis could be attributed to the greater responsibility for patient care that must be assumed by the spouse.

The characteristically distinct roles between husband and wife that resulted in the assignment of the task of dialysis to the spouse was consistent with other role differentiated tasks. The spouse's responsibility for the caregiver role made the responsibility for dialysis an "assumed" responsibility and not one that was negotiated or shared. Peterson (1985) studied psychosocial adjustment of the hemodialysis family caregiver and reported that flexibility or rigidity of roles in the pre-dialysis husband-wife relationship appeared to be a factor in adjustment to home hemodialysis. Hill (1981) discussed identification of

established patterns of relationships in order to modify care to take advantage of the existing situation, or in this case, to establish limits for spousal involvement in care.

The level of involvement in home hemodialysis was very high for these spouses because of their pre-existing traditional marital role relationships. The involved role imposed on these spouses contributed to making them feel resentful of a situation in which they felt they had no choice but to "do everything" required even though it meant they would be "burdened forever." Commitment to their marriage and their partner made it impossible for these women to withdraw from any part of the dialysis treatment without drastically altering the established marital relationship. Therefore, they continued to do what they could even though it was a difficult situation for them.

These spouses expressed a sense of loss of life as it had been, with no hope of change for the future. Changes in many day-to-day activities were reported. D'Afflitti and Swanson (1975) found similar sentiments expressed by wives of home hemodialysis partners when they conducted group support sessions for these women. These authors suggested that "dependence and control were problematic issues for this couples. In general, there was a reversal of cultural roles. The wives felt that they were managing their husbands' lives. One wife said, 'It's fine to

say it's his illness, but if he overeats and gets sick, I'm affected too.'" (D'Afflitti and Swanson, 1975, p.635).

Related to these spouses' obvious need for support are their sources of support. In this study, this group of spouses felt most supported by their adult children who lived outside of the home, and less supported from within the marital relationship. Conley et al. (1981) examined support systems of patients and spouses of home dialysis. The results in this study support the findings of Conley et al. that spouses felt that patients did not support them enough. However, Conley et al. also found that these spouses reported significantly less frequency and satisfaction with support from other family members which is inconsistent with the reports of spouses in this study. In addition, Conley et al. found that spouses received support from neighbours. The spouses in this study did not identify neighbours as a source of support.

O'Brien, Donley, Flaherty, and Johnstone (1986) reported that approximately seventy percent of end-stage renal patients had moderate to severe deficits in their sexual behavior. Age and sex did not seem to be factors. Most obviously, alteration in sexual behavior of the patient would impact on the spouse, Results from this study reflect such changes in sexuality and have been identified as concerns by these spouses.

Speidel, Koch, Balck and Kniess (1979) studied problems in interaction between patients undergoing long-term hemodialysis and

their spouses. The study included, but was not limited to, home dialysis couples. Results showed that "in their present state of affairs partners and patients describe themselves as socially much more incompetent (as defined by the Giessen test)" (Speidel et al., 1979, p.240). Results from this study show that spouses and their partners are restricted in their opportunities for socialization for reasons of less time and poor health of the partner. The spouses in this group had been reliant on their partners for socialization opportunities.

Minimal Assistants

The 2 spouses in this group were younger, both in their early 30's. The average length of marriage was 13 years. These spouses were employed full-time outside of the home. In addition, there were young children still living at home.

Duties During Home Hemodialysis. This group of spouses had the least amount of actual involvement with running home hemodialysis. All spouses took a home hemodialysis training program with their partner. The expectation was that the spouses would assist with the treatment once the partner was on home hemodialysis. The spouses in this group contrasted sharply with the previous group of spouses who "did everything" for the treatment. These spouses assisted in a very limited way.

> "Depending on how he's feeling, I don't always have to be there,"

"The only things I need to do are help putting him on and look after his needs."

Although one spouse said her duties were limited, she told about how much she disliked the job.

"And you know when I really think about it, it's not the putting him on and the taking him off, it doesn't take that long to do. It's having to wait on him. You know, we gotta resolve that because I can't handle it, I really can't. I'm going to tell him he's going to eat dinner with us or he doesn't eat because I cannot stand waiting on him. I love the man and everything else but I hate waiting on him. That may sound, I don't know, brass but that's how I feel."

In these couples the patient was relatively independent in performing the dialysis treatment. The training program emphasized the responsibility of the patient for their own care and that the spouse was there only as an assistant. Assistance given by the spouses seemed less dependent on the training and more dependent upon the marital relationship. These spouses coped with dialysis by distancing themselves from the actual procedure.

For this group of couples, the dialysis room was set up in the basement. These rooms were isolated from the main activity area of the home. The location of the dialysis room seemed to distance the partner from social contact while on the run. The rooms were very small, windowless spaces and had no extra chair

where someone might sit to visit with the person on the dialysis run. These partners both had televisions. In one situation there was an intercom system with the upstairs level of the home which further isolated the partner from face-to-face human contact and involvement.

Feelings About Home Hemodialysis. These spouses had the least amount of actual involvement with the dialysis treatment but they expressed the most resentment towards their situation. Dialysis was seen to be much more of an intrusion on their lives.

When talking about the procedure of dialysis these spouses said things like:

"It's no big deal really." (from the spouse who doesn't have to be present during the run)

"Sometimes I hate it, I really do. I come home and I think 'God, I have to do this again.'"

Descriptive words that clearly expressed the sentiments of these spouses included "hate," "scary," "fear," "gross," and "not happy." The previous group of "do-ers" expressed some negative feelings but these were tempered by some positive descriptions. The minimal assistants seemed to focus on the bad aspects and did not have positive feelings to help off-set the strong negative ones.

The spouses in this group differed from the do-ers in their cause for resentment. The do-ers expressed resentment about the

burden of assuming all the tasks and responsibilities of the dialysis treatment. For the minimal assistants the resentment was not because they were burdened by the treatment itself, but rather by the imposed lifestyle changes required to accommodate home hemodialysis and a partner who suffered from kidney disease. The resentment in this group was clearly identified and openly stated by the participants.

Relationship with Partner. This group of spouses was younger in age than the do-ers with the average age of the spouse being thirty-three years and the average length of marriage being thirteen years. Roles and relationships seemed to be much less well defined or differentiated than in the group of do-ers. One spouse talked about sharing housecleaning tasks with her partner which indicated some flexibility in roles.

These spouses differed from other participants in this study in that they did not say that home hemodialysis brought their relationship closer together or resulted in increased support between them. The difficulties and changes resulting from home hemodialysis resulted in marital strain. The researcher got the impression that the situation for these couples was fragile at best and that either the marriage or home hemodialysis would eventually have to end due to the stress. One spouse implied that they had problems within their marriage and said that "some of our problems are related to dialysis but not all of them." Another

woman alluded to a separation or divorce although she stated it was not presently an option for them.

"I think what I could be doing if I was on my own and I do have the choice to leave but I won't do that."

Communication. These spouses talked about problems with communication that directly affected their marital relationship.

"It was getting to a point in our marriage where he wasn't talking to me or anything - we just weren't communicating."

"I really forced him to talk. We had alot of problems and we needed to talk."

"He didn't want to admit we were having these problems and he refused counselling."

These relationships seemed to have less sharing or less "give and take" between the partners, not only in the task of dialysis but also in communication.

"We're having a problem dealing with meals. He doesn't want to compromise so we're having a disagreement. I'll get my way, I usually do."

Because these spouses had difficulties in communicating with their partners they tended to develop feelings of tension within themselves.

"If you keep it inside, it keeps building up."

"I never talked about it [home hemodialysis] - just carried on and I think it just kind built up. I got really depressed."

These spouses thought counselling, self-help groups or peer support groups might have helped them overcome some of their troubles with communication, or could have helped them deal with their situation better. However, these spouses did not actually seek help. They gave reasons for not obtaining outside help because their partner refused to go along or they did not have enough time.

Presence of the Partner. These spouses did not say that the presence of the partner was a positive outcome of home hemodialysis. On one occasion one spouse commented that she liked having her partner home for the children since she was often at work. Presence of the partner for the sake of companionship was noticeably absent in this group.

Protecting the Partner. Except for this group, all spouses spoke about ways in which they indirectly protected their partner. The absence of any comments or discussion on this topic therefore seemed significant. It could be that the whole situation was so terrible for these spouses that they were at a level where they first had to think of themselves and protect themselves from the imposed unfortunate situation. One spouse said:

> "Why do I have to do this, in terms of I and not we. I don't really think about [my husband]. I think what I could be doing if I was on my own and I do have that choice to leave but I won't do that."

Day-to-Day. The role each of these spouses assumed in the actual treatment accounted for differences within this group. One spouse who said she "doesn't always have to be there" spoke very little about day-to-day management of dialysis. Her minimal level of participation was reflected in statements such as "It doesn't affect my time" and "I'm free." She said that when her partner was hospitalized it was very difficult for her to accommodate the demands of her job, the house, her children and visiting her partner. However, now that her partner was home and relatively independent with home hemodialysis, the demands on her were much less. Minimal participation and involvement meant that this spouse had much less time to share with her partner and she did not feel as committed to dialysis. Because of her minimal role in home hemodialysis, she could not articulate changes in day-to-day activities that had been changed due to home hemodialysis. By not being involved, this spouse was able to distance herself from the treatment and other day-to-day changes (such as diet modifications for the partner, sleep, scheduling of time).

The other spouse in this group was not actively involved in all of the dialysis treatment but she was always in the home during the dialysis run. For this spouse, time was a crucial element in managing home hemodialysis and in feelings of resentment towards the treatment.

"Time is such a problem - not enough hours in a day. I don't have any time for me. For me to take time for me I would lose out on something else that has to be done. I'm really losing alot of time here."

This spouse held a job where the hours were flexible. Rather than being optimistic about the flexibility of her job she saw dialysis as drastically cutting in to her employment (work time).

"It's a big change to lose my own time. I miss my freedom. There's resentment."

Trying to manage all the demands on her time was difficult.

"Having to deal with him (home hemodialysis), my job, the house - I feel buried."

She commented that her life was hectic, she always felt rushed and that made her grumpy. Attempts to improve the situation included scheduling herself to always be home by five o'clock on dialysis days so it was not too late at night. Since the evening meal, clean-up, child care and dialysis all occurred within the same time period, this spouse felt torn in several directions and continuously rushed and frustrated. She was not aware of strategies to improve her situation.

"I haven't really thought about it [scheduling]. Maybe that's why I get so tired of it [dialysis]."

She thought that coming home earlier and getting a housekeeper would have helped but she still needed to be home during the run and would therefore feel the loss of freedom.

This spouse saw her own hospitalization for surgery as "a nice break." Seeing surgery as a way to "just get away from it all" indicated that this spouse needed a break from her situation.

These spouses did not talk about meal planning or any diet changes related to home hemodialysis. Again, this seemed to be an indication that these spouses were less involved in overall treatment and that their partners were independent in managing their own diet and fluid restrictions.

Socialization for these spouses was not as limited as for the do-ers since these spouses had socialization through work. However, as a couple, their socialization had been reduced and changed.

"Now we do alot of socializing in our home."

"One thing I found really difficult to deal with is his body wouldn't let him do as much as he would want to do so therefore it goes back on me too because we couldn't go dancing or, you know, go skiing or something like that because he is just too tired."

"I love to go out dancing on a Saturday or something and we usually don't go because [my husband] may be too tired.

We've gone out for dinner a few times but we don't go out a lot."

"I find that dialysis gets in the way of some things that I would want to go to and can't because I have to be home."

Holidays were problematic for these families. One family had to cancel a trip to the Caribbean that had been planned prior to initiating home hemodialysis. The cost of dialysis prevented them from accessing the required services outside the country.

Attitudes towards dialysis affected even planning stages of a holiday.

"It would be a pain having to do dialysis on holidays."

The family who cancelled their trip to the Caribbean were not re-organizing their holiday time or plans. It seemed these people viewed dialysis as incompatible with holidays.

One family did make detailed plans to travel across Canada with pre-arranged dialysis treatments along the route. The partner got very ill and had to fly home part way through the holiday. The spouse had to drive back with the children. This "disaster" left everyone feeling worse than before the holiday. They had expectations that

"things were gonna be great [on holidays] and then the walls just came crashing down."

No attempts, thwarted attempts or failed attempts at holidays made a bad day-to-day situation worse. Seeing no available

options for the treatment combined with less opportunities for a break or a holiday, were causes for resentment.

Support. Consistent with the spouse's role of minimal involvement in home hemodialysis of their partner, these spouses said their support came from persons other than their partners.

"She [my mom] helped me through a lot of it. I could always go there and talk to her and cry."

"Our friends are supportive."

"My sister, mostly."

"Even co-workers, they're very good. Just even putting their arm around you sometimes when you're really down."

One spouse said that she was depressed about the whole situation, including her partner's poor health, and her physician prescribed anti-depressants to help her cope with the depression. Counselling was recommended but not undertaken because her partner refused to co-operate.

Extra diversionary tasks that helped the do-ers cope with the situation were not at all helpful for this group of spouses. In fact, tasks involved in daily life were cause for frustration and extra tasks would only add to the troubles. One spouse said the kinds of things that made her cry were

"Having to contend with my job as well as home life and with dialysis, now that's another thing I have to deal with. And

sometimes I feel like everything is just building up on top of me."

Coping with home hemodialysis requires time, energy and resources. These spouses had very little available time or energy to seek out supplementary sources of help.

"I'd probably go to a self-help group, or something like that and . . . just go and talk to other people who are in the same situation and maybe that would help. But to spare the time, it just can't be done."

Perspective. The partners in the group were awaiting a kidney transplant so these spouses saw home hemodialysis as a temporary measure. Their hopes were for a kidney transplant to relieve them of the terrible situation. Perhaps this may have been part of the reason that these spouses had difficulty integrating dialysis into their lives and becoming actively involved with it. These spouses were not committed to the dialysis treatment.

"If I felt that this was going to be a real long-term thing . . . I'm not thinking of it in those terms."

"I dread the thought of having to do this for a great length of time. I can't see us doing it for six years."

"Hopefully a kidney will come up soon."

This group of spouses also saw home hemodialysis as the only choice of treatment at this time.

"If we didn't do home hemodialysis he would die. No choice - we're waiting for a kidney."

"Until we get a kidney, or until it's dealt with - we can't do anything about it."

"Dialysis is part of [my husband]. It's his health, it's like keeping him alive."

Summary of Minimal Assistants. The minimal assistants participated marginally in the actual dialysis treatment of their partners. Disruption of their lives, imposed by home hemodialysis and kidney disease, resulted in strong negative feelings. Resentment was a result of their situation in general and not specific to dialysis treatment. One spouse managed dialysis by physically distancing herself from the treatment and other related aspects of kidney disease management. Another spouse didn't physically distance herself but expressed many frustrations and resentment towards the role she did play. Changes in day-to-day life were difficult for these spouses to contend with. External responsibilities of full time employment were added to home management, childcare and dialysis which resulted in these spouses feeling over-stressed. It is possible that these spouses lacked commitment to the treatment and possibly to their partners.

Discussion. A lack of involvement by these spouses was shown by their lack of contribution to day-to-day management of such things as diet, and in the absence of expressions of caring,

sharing and support for their partner. However, distancing themselves from the treatment through lack of involvement did not relieve these spouses of feelings of resentment towards their situation. The pervasive negative feelings about how home hemodialysis had affected their lives in general showed that these spouses had a particularly difficult time attempting to incorporate dialysis into their lives. Strauss (1986, p.11) wrote about chronic illness being "disproportionately intrusive on the lives of patients and their families."

The lack of involvement by these spouses may have had multiple explanations. Lack of involvement may be attributed to lack of commitment to the treatment. These spouses were both waiting for transplants for their partners and did not view home hemodialysis as the ultimate treatment. A lack of involvement may also have been due to lack of commitment to their partner. These spouses expressed concerns related to the weakness or strain in the marital relationships. Brackney (1979) conducted a study on the impact of home hemodialysis on the marital dyad and found that conflict between two partners, either general marital conflict or conflict specifically related to dialysis was potentially disruptive to the marital satisfaction of both partners. The direction of this interaction cannot be specified but there seems to be a relationship between resentment (of the marital and/or dialysis role) and lack of cooperation during dialysis. Brackney

(1975, p.58) noted that "the assistant's marital satisfaction was positively associated with the patient's assessed ability to work cooperatively with his spouse during dialysis." The minimal assistants lack of involvement meant they did not work cooperatively with their partners which may have been a reflection of pre-existing and ongoing decreased marital satisfaction.

Other authors, including Lowry and Atcherson (1980), Strauss (1986) and Wright and Leahey (1987) have identified that chronic illness can be an immense strain on marital relationships and that "results can be catastrophic - or, conversely, successful" (Strauss, 1986, p.17). The spousal responses in this study show that for the minimal assistants, marital strain was a result of their experience with home hemodialysis. Rosser (1982, p.162) suggested that families adapt to dialysis in similar stages as do patients. Maladjustment to dialysis occurs when families or patients "fail to reformulate their life in a meaningful way, generally because of previously fragile adjustment."

Another cause for a decreased level of involvement was identified by the spouses in this group. The roles outside the home assumed by these women made it difficult for them to manage all the work that was required of them at home. Full time employment outside the home, household duties and childcare left less time and energy for these spouses to invest in home hemodialysis. Strauss (1986, p.16-7) wrote.

> A major problem that confronts the ill and their families (or at least the spouses, whom we are studying) is the juggling of three lines of work. There is the work of managing the illness. But, unlike the hospital situation, one or both spouses also have to manage the details of everyday life: the housekeeping chores, the rearing of children, and so on. In addition, each spouse is trying to live his or her life, both separately and hopefully together, despite the exigencies of illness.

The minimal assistants were heavily burdened with many roles and this may have been partly responsible for their lack of involvement in home hemodialysis. O'Brien, Donley, Flaherty and Johnstone (1986, p.313) suggest that in families of end-stage renal disease patients there may be "weighty and unexpected role behaviors and responsibilities" laid upon the spouse which can result in "disorganization or even disintegration of the family as a functional system."

The minimal assistants expressed that they had "down days," felt grumpy and experienced depression. In fact, one spouse sought medical assistance for treatment of depression. Such feelings are not uncommon in families dealing with ongoing, stressful situations such as home hemodialysis. Lowry and Atcherson (1980) studied home dialysis dropouts and found "the not infrequent occurrence of emotional problems (especially depressive

disorder) among both patients and spouses during the course of home hemodialysis training and treatment." Similarly, early findings by Shambaugh et al. (1967) showed depressive disorders in spouses of home hemodialysis partners.

Similar to the group of do-ers, the minimal assistants reported loss of socialization opportunities due to lack of time and poor health in the partner. These spouses felt their social possibilities were lessened by their partnership with a chronically ill person. Speidel, Koch, Balck and Kniess (1979) examined social interaction between patient and partner and found that spouses of patients seem to see themselves suffer in terms of social possibilities even though their individual social possibilities were still seen as relatively high.

The Joint Partners

The spouses in this group ranged in age from 36 to 66 years. The marriages in this group were longstanding ranging from 18 to 36 years. The spouses in this group varied in employment status including retired, part-time and full-time. One couple still had children living at home.

Duties During Home Hemodialysis. The third group of spouses has been called the "joint partners" because their involvement in running home hemodialysis was one of sharing tasks with their partners. These couples had been running home hemodialysis for an average of six and a half years. Within this group there was

variability in what tasks each spouse did as part of the treatment but they all expressed the view that the treatment was one they were involved in with their partner. The joint partner's role in dialysis was primarily related to psychological support of their partner throughout the treatment. While acting as support persons these spouses were also involved in assisting with particular dialysis tasks. In contrast with the minimal assistants who said "it's his problem but I'll help him with it," this group of spouses viewed home hemodialysis as a problem they shared with their partner.

"We want to do it together."

"I sit with him for the four and a half or five hours and do runabouts, which is fine."

Since these spouses were involved with the treatment they did not leave their partner alone during a run, but always remained in the vicinity. However, these spouses did not express sentiments that dialysis made them feel tied-down or restricted.

These families had a separate dialysis room but it did not seem isolated from the rest of the house and more importantly, from those who shared the job of dialysis. One family had the dialysis room in the basement by the family room. While on the run the partner helped the children with schoolwork and the children joined him to visit, watch television and play games. The partner was not isolated from "normal" family affairs and

indeed played a central role. For the other couples, there were no children living in the home. One spouse sat with her husband "watching the news, conversing and reading" while her husband was dialyzed.

Feelings About Home Hemodialysis. These spouses had a more positive outlook towards their situation than did the previous two groups. Certainly, the situation was not always good for these people but they maintained an optimistic view with a sense of hope for the future. Because of the shared nature of their role in dialysis they felt less burdened by the full responsibility of dialysis yet involved enough to clearly understand the treatment and how it was for their partner. These spouses felt they contributed to the well-being of their partner which gave them a sense of pride and personal accomplishment.

Feelings of fear and anxiety were expressed by the joint partners. These spouses identified their fears as being directly related to the machine and the treatment but they had been able to share these fears with their partner and worked at decreasing their fears by being involved. They said

> "It [home hemodialysis] wasn't as bad as I thought."
>
> "Problems on the run are upsetting but we managed to control them ourselves."

Success with managing problems during a treatment gave these spouses confidence that they could deal with home hemodialysis.

Sentiments about home hemodialysis expressed by these spouses included "wonderful," "convenient," "comforting," "reassuring," "a Gift of God" and "it's a freedom." These spouses generally viewed home hemodialysis as a means by which they and their partners moved towards a "normal" life. Therefore, home hemodialysis "gave" them life and freedom. This positive outlook was reflected in less feelings of resentment. In contrast, those spouses in the minimal assistants group saw home hemodialysis as incompatible with their "normal" life and it was cheating them of what should be "normal."

Relationship with Partner. This group of spouses had been married to their partner for an average of thirty years. These marital relationships were characterized by strength in the bond between the two persons. The mutual "give and take" for tasks of dialysis arose from the established nature of their relationship which was one of sharing. Spouses "appreciated" helping their partners because they felt that was one way they helped share the burden their partner had to bear and it strengthened a pre-existing closeness.

> "It's good for me to know, that he knows that I'm there. You really do tend to appreciate each other."

The closeness of these relationships was strengthened, not threatened, by home hemodialysis.

> "Such a disaster brings a couple much closer together."

"Our closeness has become much stronger emotionally."

"This is another binding part of your life."

"We're closer than alot of couples. He knows I'll be there."

"You've got more than just a marriage, you've got a relationship that depends on it. It's a stronger union."

These spouses did not feel they were giving more than were receiving by doing home hemodialysis. These spouses all thought that sharing home hemodialysis made them feel more involved and gave them an awareness of dialysis as part of their partner's life. The fact that they assisted with home hemodialysis gave them a sense of well-being. Assisting with dialysis was an extension of the mutuality of their relationship.

"It's a feeling we're licking this together. I'd feel left out if he ran at the hospital."

For these couples, the dialysis partner accepted the responsibility for the treatment so the spouse felt less burdened. Sharing tasks resulted in a feeling of sharing the burden which made the spouses feel good. By feeling less personally burdened, these spouses had less feelings of resentment towards the dialysis treatment.

Communication. These spouses also communicated and shared feelings. The relationship was based on reciprocal support between the spouse and the partner.

"My husband is very strong - he helps to uplift me."

"I cried alot. I didn't have to hide this from my husband. Sometimes he'd cry with with me."

"He has a good outlook. His attitude helped me."

The open communication was consistent with the sharing type of relationship and that was supportive to the spouse. These spouses were able to vent frustrations, anger and concerns about home hemodialysis with their partner without feeling they were risking the relationship.

"[Anger] . . . I let mine out. I didn't always say everything I wanted to at the hospital, I would give the impression. They would know that something was upsetting me but then I'd probably spend an hour afterwards telling [my husband] 'I should have said this' and 'They don't know' and maybe he took the brunt of all this anger. Maybe I was doing it so he would know that I feel this way too."

For two of these couples joking, teasing and laughter were ways of sharing, communicating and coping.

"He's kept a sense of humour and I think we've had lots of laughs over things that could have been quite serious at the time."

"We joke about our ugly feelings."

None of the other spouses said that joking or laughter entered into their experience with home hemodialysis.

Because they had shared so much and knew each other so well, one couple had "unconsciously" developed a means to communicate bad feelings in a way that was not threatening.

> "I fine-tuned my dirty looks because if there's any thought in my mind that he's going to say something degrading to me I have this look that I give him and you know he realizes that he's getting under my skin. We do that. And I suppose it's the same thing when he says I'd like some soup and maybe I'm just near the near the end of the chapter or something and I sit there and he's got the same look. Like he means now. So we have this look that we know is important and serious and we're not fooling around here."

While these relationships were strong and showed the best adjustment to home hemodialysis, these spouses talked about the difficult times - the "hairy years."

> "The emergencies would happen and then [my husband] and I would argue alot. I would feel this should be done and he wouldn't and we didn't handle these discussions too well. We'd get pretty cross with each other and the kids would hear that and then they'd know that I was going to be upset."
>
> "You know man and wife, the husband, friends or anything can

get mean with each other sometimes and I think that's what happened, we just got kind of at logger heads about this. I don't know, anyway it doesn't happen now because I have that confidence and [my husband] is aware that it's a whole different feeling with us now than to begin with."

The spouses in this group had confidence in the way they managed their situation so they were able to talk freely about the bad times. They seemed realistic in the appraisal of their feelings towards their partner.

"I got so infuriated and yet at the same time you had sympathy for this person but you know that anger is not really at you, it's the frustration of going on the machine, needling, it's the high tension period of time and there are only two people there so if anybody's going to snap you've only got one other person to snap at."

"They [dialysis patients] do tend to become depressed and withdrawn so you have to sit down and really talk to them. And it's really hard to say things like that because you sound like you're mean but yet I'm not trying to be mean. I'm trying to snap him out of whatever it is he's in. But [my husband] doesn't tend to be that way very often. I think I get the opposite. I find that when he's depressed, because it's not very often, you feel that you really try hard to get him over that stage. It's almost like a challenge."

Presence of the Partner. Presence of the partner during dialysis at home was very important for the joint partners.

> "The biggest plus [for home dialysis] is having him here with us."

These spouses appreciated having their partner at home not only as company for themselves but also for the sake of their partner.

> "Just for him to be here that I can see him and that he knows that we're here."

Spouses also liked having their partner home because then they knew what happened during the run and they knew how their partner felt.

> "So that's consoling to me, just the fact that he's here and when he's off, he just comes upstairs and he's right here. I know he's safe and he's fine and I don't worry about the things that could happen."

> "My main concern was to get him here in the family setting, so the kids would be around, I would be around, and we would watch him and it's worked out really well. He does his work and he can talk on the phone. He can watch T.V. He often sits with the kids and he reads stories and he does homework with them and all those things so I think he feels that he's here still."

Protecting the Partner. The sharing relationship afforded a closeness that resulted in more openness in communication and therefore less shielding of the partner. These spouses protected their partners from concerns outside the relationship.

> "He did not have much endurance then so wherever I could I did all the night duty [in their employment partnership] so only if [a certain task] was necessary my husband would get out of bed at night . . . . I learned to live with less sleep but I felt it was so much better having my husband rested."
>
> "[My husband] was quite ill . . . . The fistula was clotted, I was panic-stricken because there was no way he could even dialyze until something was repaired and I got [my daughter] up and we went up to the hospital, up to Emergency. I guess it was about 3 in the morning when we got there. They immediately wanted a chest x-ray and I said 'No.' He just had a chest x-ray at 5 o'clock that afternoon. Well they didn't have a record of it. Well, I got so mad, I roared and screamed and I said 'You go send somebody up and you find this x-ray. You're not going to just take him. He's sick. He needs some help.'"

By representing her partner, this spouse protected him from, what she thought, were unnecessary procedures. These spouses acted on behalf of their partners, when they were unable to do so themselves.

The spouse who worked outside the home protected her partner from problems she encountered at work.

> "I know that he's got alot on his mind too, so to come home and to chat about work and what went wrong - No. I don't go crying to him or making like it's been a real bad day because I think he's got enough of his own problems, he doesn't need to hear all of these."

Day-to-Day. There was variability in the day-to-day management of dialysis within the group of joint partners but all the spouses in this group talked about how "normal" their lifestyle had become.

> "And he thinks 'what do other people at his age do when they come home from work?' They also sit down, look at T.V., read the paper, have their wife supply them with a good evening meal. He can have friends. And he can telephone and do all sorts of things with his one arm."

> "He usually watches television. I read, and read. We converse. We play games. It's so matter of fact now, you know. We've been at it for almost eight years now, that it's kind of like the laundry that has to be done. It's just one of those jobs that has kind of worked their way into our lives."

In the group of joint partners, one spouse was retired with her partner, one spouse worked part-time and her partner was

employed full time and one couple both worked full time. These spouses all had education for professional careers. All the spouses expressed satisfaction with their position in the work world. The retired spouse said "that's our lifestyle now." This couple had prepared for their retirement and had been able to accomplish their goals, despite hemodialysis.

> "We have arranged our lives in such a manner, actually before we ever got onto the machine. We came to [the city] because we could not live in the country we thought with his condition. We also looked for the house which we would like to live in once we could not move very much or travel anymore so that it could be an eternal holiday once we retired and that's what it is."

The spouse who worked part-time enjoyed her work very much and found personal satisfaction in her job. In addition, it offered a "social" outing. Her workplace was supportive and she did not have conflicts between work, home and dialysis commitments.

> "I was working at [an office] when this all started and they've done everything they can. You know if an emergency comes up . . . my supervisor just said 'OK, take a week of absence until you get straightened out.' They've been very good about my time for dialyzing, they wouldn't ask me to work you know . . . . My friends at work were very

encouraging to me. They'd say 'Oh you'll be able to do it you know, everything's going to work out fine.' They were concerned and encouraging."

The third spouse worked full time and also gained personal satisfaction from her job. She wanted to work at a job she had been trained for.

"I've got training, I've gone to school. I've got a degree so I'll work."

In addition, her job ensured that she had such a busy lifestyle there was no time left to dwell on the home hemodialysis situation.

"I don't want to stay home. I did stay at home for a long time with the kids and when our youngest went to school I went job hunting. I found you did think about it alot, you did start to feel sorry for yourself. So maybe it's because I am working and the lifestyle is a busy lifestyle, you don't dwell on it as much."

For the two spouses who worked, their employers were aware of the home hemodialysis situation and it was helpful to these spouses to know that their work could take lower priority than their partner if the demands of both could not be met.

Because the partners took responsibility for their own treatment, these spouses did not play a 'controlling' role in diet management. However, because they were involved and cared about

their partner, they planned meals to accommodate them. They made changes in buying and cooking habits but did not give the impression that this was a burden.

> "You know I'll make two little meal types and just say to everybody pick which one you like because I know which ones the kids will go for and I know which ones [my husband] will go for and luckily he doesn't crave salty things. He doesn't like chips and things like that so it worked out OK for us. I just try to stay away from a lot of the salty stuff and it's just - we've adapted to it really well."
>
> "I'm very careful with what I cook. He can have some salt but I've changed my way of cooking."
>
> "I don't buy bananas and I don't buy oranges, but someday I'm going to shrivel up from lack of potassium because I . . . at least I won't tempt him."

Again, this aspect of daily life was characterized by sharing of responsibility. The spouse planned and cooked meals keeping her partner's diet and likes and dislikes in mind but didn't feel the burden of responsibility for what the partner actually consumed.

Lack of sleep was not a problem for the spouse who was retired but she said that sometimes she lacked sleep due to late night dialysis runs. Her lifestyle permitted day-time naps to make up for lost sleep.

"I certainly didn't get enough sleep at times but I've done this all my life for other people too. I could sometimes have a good snooze in the other bed during the day and that recovers you. It just puts life into you again."

The spouses who were employed commented on lack of sleep. Because the spouses and their partners both worked during the day they ran dialysis in the evening which meant they got to bed late on dialysis nights.

"I find probably the hardest part is staying up late. It's probably a later night than most people put in. So a five hour run, it's 12:30 and then by the time he's off and lately he's been having a bit of problems with the clotting so it's 45 minutes before we can get one needle to stop. So there's times that we've gone to bed at twenty to two. So then you get up and go to work the next day and we both have very, very busy jobs so you're really tired come the next day and you don't feel like doing too much."

Having late nights on a consistent basis, three times per week for years, was something these couples endured, not adjusted to. Ongoing fatigue is physically draining. One spouse said since home hemodialysis she had taken more sick time from work because she needed rest.

Variability within this group was also reflected in their time management. The spouse who was retired said their life was

more settled than when they had both been working and that they were "not always looking at the clock."

The spouses who worked had more obligations for their time and therefore had developed more organization and schedules to help them manage the home, family, dialysis and their work. The fact that these couples had done home hemodialysis for an average of six and a half years is indicative of the success these spouses had in incorporating dialysis into their "busy lives."

> "I don't know what normal families do 'cause I think to myself 'if we had five nights a week plus the weekend gee we would really get alot of things done rather than trying to get everything done Tuesday and Thursday.' But we've done it for years and we've managed to get it done so I guess it will work in two nights the same as five."

The overall positive attitude of these spouses towards home hemodialysis was reflected in their outlook on holidays. They felt that having the knowledge and skill to run home dialysis gave them the freedom that permitted them to go on holidays. The retired couple adjusted by going on more frequent but shorter holidays.

> "One doesn't always think of this [without dialysis my husband would be dead] but when one thinks of it one is full of joy and very grateful that one has one another and that we can still do these things and whatever we can do we probably

enjoy more than we would have done had there been nothing. For instance, last summer went to Lake [Clearwater]. We had the camper with the built in kidney for a week and we went to the Rockies."

This spouse also stated that they had frequently travelled prior to home dialysis so they were not missing travel opportunities. They had capitalized on opportunities and good health in their earlier years. Now, their lovely retirement home "is an eternal holiday."

One couple travelled to different locations in the United States to visit family and enjoy vacation time. They took the initiative to preplan and organize these events. Hemodialysis decreased the length of their holidays but it did not eliminate them.

The third spouse stated that their vacations were family oriented and they all enjoyed camping. They rented the Kidney Foundation Winnebago and

"we do things all day and then in the evening right after supper, we basically keep the same schedule on a holiday as we do at home."

The perspective for this spouse was that holidays worked well and were a "normal" part of family life.

Only one of the spouses in this group commented on the topic of sexuality. She said

"Our sex life has pretty well stopped. We've never really investigated into it. Our closeness has become much stronger emotionally. It's changed sex but it hasn't changed love. Like, you know, neither of us seemed to be too concerned about that."

Perhaps these relationships are so well established and secure that they can tolerate such changes without disrupting the bond between the two persons.

Support. The strong marital bond found in these couples was a source of support for these spouses. The communication between spouse and partner helped them share the good and bad times and thereby support each other. A commonality found in this group was that they did not talk about kidney disease and dialysis with their children or their extended family.

"I didn't feel free to talk to my children. It was very expensive to talk to my sister constantly."

"When you have worries you don't want to burden other people with it and I'm only so glad that my parents did not live long enough, that they did not experience the problems we were in."

"It's very hard to explain to people and it's different if they come up and ask but you don't want to throw it at your family or at his family. It's very unfair to constantly talk about it, so we don't. If they ask us questions we'll answer

them. It's not that we're snubbing them it's just that we make out to be a normal family and if they want to come and ask a question, fine, we're very open."

This finding is in contrast to the do-ers and the minimal assistants who relied on their children and extended families for support, rather than from the marital partner.

There was some variability in how the joint partners coped. One spouse found that the outside activity of silversmithing was one way she could "forget her worries." Another spouse did alot of reading, including information on kidney disease. By increasing her knowledge she felt better able to cope with her situation since "the more you know about it the less frightening it is." One spouse maintained that keeping busy was one way of coping with the situation.

"I don't give us the chance to sit back and really dwell on it and feel sorry and I think that is the best way to get around it. I don't want to sit and mope and think about it all the time. It's there, I know it's there. I'm certainly conscious of it but I'm not going to think about it all the time. I can't change it so why would I sit and become so depressed over it that I would just take everybody with me."

To maintain what these spouses perceived was a "normal" life required that they relied on their partners for support.

Perspective. The partners in this group had been on dialysis between four and eight years. While all the partners were on the transplant list, the spouses realized that their partners might never receive a transplant. Having adjusted to home dialysis these spouses did not see an urgent need for a transplant. One spouse even dreaded the prospect of a transplant.

> "Something I do dread should he ever want to have a kidney I know he is not a good patient. He won't eat in hospital so if he wants to have a kidney he would be deep down in the dumps again. So, that is what I would dread."

This spouse had the view that home hemodialysis had "all given life, extra life which is nice for me and it's very nice for him." Her perspective on dialysis and the future was influenced by her positive feelings about the present situation which were

> "You can only be pleased if you've made your peace with your fate and my husband's fate is not a bad one."

The other spouses in this group did not express dread at the prospect of a transplant but nor did they seem overly hopeful that it would be "the answer" to their life with a partner with kidney disease. Their expressed sense of hope was related to the good life they experienced and maintenance of the status quo, that is, no deterioration in health of their partner. Because they managed so well with home hemodialysis they did not have the urgency for a change in their situation. One spouse said that "we don't dwell

on it [home hemodialysis] and I don't often think about the future." This spouse had made dialysis part of her life but resisted making it all of her life by keeping involved in outside interests (her job) and her family life.

Summary of Joint Partners. The joint partners shared the responsibilities of home hemodialysis with their partners which was typical of their cooperative relationship. These couples shared duties related to the treatment, feelings, responsibilities and burdens. The spouses assumed additional caregiving responsibilities but maintained activities outside the home as well. While the spouses were very involved with home hemodialysis of their partner, they did not orient all their activities towards the partner's illness and dialysis treatment. In this way home hemodialysis did not "overtake" all their life so they felt less resentment towards it. These spouses thought that home hemodialysis permitted their partners to be well enough to enjoy their life together. Being able to integrate home hemodialysis into their lives gave these spouses a sense that they were able to maintain "normalcy" in their lifestyle. Strong marital relationships provided both a reason and a means to manage home hemodialysis effectively.

Discussion. The spouses who were joint partners were more successful in accommodating home hemodialysis into their lives than the do-ers or the minimal assistants. The joint partners

expressed little resentment towards home hemodialysis and were more adjusted to both the treatment and the altered lifestyle. Craig and Edwards (1983) developed a conceptual model for nurses on the process of adaptation in chronic illness. The focus of the model extended beyond the patient to include the family. Craig and Edwards (1983, p.402) suggested that

> ". . . the key factors of adaptation are a hopeful perspective, a sense of control and competence; a sense of being needed; and the maintenance of self-esteem, personal worth, and human dignity in the face of impaired functioning."

In these ways the joint partners adapted to home hemodialysis. They expressed hope for the future and had an optimistic perspective on their lives. They focused on the "normal" aspects of their lifestyles not the ways it had been drastically changed. These spouses also had confidence in their capabilities to assist with dialysis treatment. Joint partners believed that home dialysis gave them, and their partners, control in their lives. The cooperative relationship between husband and wife gave these spouses a sense of being needed. This was in contrast to the do-ers who felt totally responsible and therefore burdened and to the minimal assistants who were so marginally involved in the treatment they lacked commitment to it. Finally, the joint spouses maintained self-esteem and personal worth in their lives.

The strong marital relationship, their families and their careers contributed towards the spouses feeling good about themselves.

The strong, cooperative relationships with their partners influenced the joint partners' experience with home hemodialysis. The results from this study support Brackney's (1977) findings that showed the marital satisfaction of the spouse was positively related to adjustment to home hemodialysis. Brackney also reported that the spouse's marital satisfaction was positively associated with the ability of the couple to work cooperatively during dialysis. The results from this study show that the joint partners who worked cooperatively during dialysis had strong marriages and felt less resentment. The spouses who under or over assisted with dialysis treatment reported less positive feelings about their marriages and expressed more resentment towards their situation.

The joint partners were similar in that they all commented on the "normalcy" of their life. They had developed strategies and attitudes that promoted incorporation of home hemodialysis into their lives. The treatment had become routinized and the positive outcome was that these families could carry on what they perceived to be "normal" lives. Their perceptions of normalcy relieved them of feelings of resentment. O'Brien, Donley, Flaherty and Johnstone (1986, p.313) attributed "normalcy" to denial.

> "Although survival with end-stage renal disease is susceptible to romantic portrayal, it is not a "normal" situation and the life on chronic dialysis is not a comfortable one. Frequently, however, the gravity of the condition appeared to be denied by caregivers, family members and even the patients themselves in order to facilitate the task of daily living."

These authors also suggest that negative consequences result from attempting to normalize the situation. Prohibiting expression of emotions such as anger, anxiety, and frustration imposed by the illness and the dialysis treatment may be detrimental. Results of this study do not support denial as a reason for normalizing by the joint partners. The joint partners were able to express frustrations, anger and anxiety. They did not indicate evidence of denying their partner's illness. The fact that home hemodialysis had been managed for an average of six and a half years by the joint partners makes it unlikely that denial was the sole cause of perceptions of normalcy.

Strauss (1986, p.79) believes that a goal of chronically ill persons is to live as normally as possible despite the disease and its' treatment. From Strauss' viewpoint, the perceived normalcy of the joint partners' experience with home hemodialysis attests to their success in managing the intrusive treatment of dialysis.

For the do-ers the burden of dialysis work, and not the departure from a "normal" lifestyle, was cause for resentment. The do-ers perceived minimal lifestyle changes and said their lives were "near normal." While the do-ers were relatively successful in meeting Strauss' goal of normalcy, the means to achieve it were overwhelming.

The minimal assistants perceived that their lives could never be normal as long as they were doing home hemodialysis. The dialysis treatment prevented them from achieving the normalcy goal they wanted. Because dialysis was seen as the block to them leading normal lives, the minimal assistants were resentful of it.

General Discussion

From the preceding descriptions and analysis of the three types of spouses, it is evident that the experience of the spouse as the designated helper in home hemodialysis is affected by, and affects, all aspects of daily life. Variability between spouses was reflective of variability between individual personalities, marital relationships and general life situations. However, three groups of spouses could be distinguished based on their involvement in dialysis treatment and on their level of resentment evolving from it. Based on these two categories the model, which has previously been discussed, was developed. However, a third factor related to the marital relationship appears to be very closely linked and in fact, may be the underpinning of the whole

experience. The marital relationship affects, and is affected by home hemodialysis.

The purpose of the present study was to examine the experience of home hemodialysis from the emic perspective. The spouses talked about their role in dialysis, their feelings about it and how it affected their daily lives. From these data a combination of two factors, level of involvement and level of resentment, describe most of the social-psychological variability in the experience. Analysis of the results shows that the pre-existing and ongoing marital relationship is a pervasive influence on the experience of home hemodialysis. Brackney (1979) suggested that there is a reciprocal interaction between marital and dialysis related roles on the part of home hemodialysis partners and their spouses. The purpose of this study was to examine the spousal experience with home hemodialysis and not marital relationships as influenced by home hemodialysis. Therefore, the results focus on the treatment as affected by marital relationships.

The joint partners portrayed their experience with home hemodialysis as growth-promoting. They said that they had grown closer together as a couple through the shared experience of home hemodialysis. The do-ers also considered their marital relationships to be stable and enduring but this was in spite of dialysis and not because of dialysis. The minimal assistants

showed that marital relationships were strained and possibly at risk because of dialysis.

	Type of Involvement	Influence of H.H. on Marital Relationship
Joint Partners	co-operative	strengthened, improved
Do-ers	over-involvement	endured
Minimal Assistants	under-involvement	strained, at-risk

Figure 2

Marital Relationship and Level of Involvement

MacElveen, Hoover and Alexander (1975) found that cooperation between spouse and partner was a significant factor in patient outcome success. Patient outcome success was assessed by physical status, adherence to treatment regimen, total activity, morale and positive effect. This present study reveals that cooperation extended beyond patient success parameters and is also important to the success of home hemodialysis from the perspective of the spouse helpers. Success means adapting home hemodialysis into one's life. Family theorists (Hill, in Walker, 1985) have

suggested that interdependence, reflective of cooperation in tasks, promotes adaptability. Adaptability has been defined as

> "a flexibility and willingness to shift social roles, acceptance of responsibility by all in performing the tasks, habits of collective discussion and control, and repetoire of crisis-meeting devices" (Walker, 1985, p.831).

The joint partners were interdependent in tasks of hemodialysis, that is, they worked cooperatively to manage the dialysis treatment. If one can take the quantum leap that lack of resentment is an indicator of adaptability, than the joint partners who showed least resentment, were most adapted. The do-ers accepted total responsibility for their dependent partners. These couples showed much less flexibility in roles and very little sharing of tasks. Lack of adaptability according to Walker's definition was reflected in the increased level of resentment in this group of spouses. Similarly, the minimal assistants, who accepted very little responsibility for dialysis treatment, were resentful. The partners of the minimal assistants were independent with dialysis and not interdependent. These families were much less adapted to home hemodialysis.

McKee (1977) investigated the effects of hemodialysis on locus of control, dominance and affiliation and evaluated changes in these personality dimensions as a function of home dialysis training. Results for locus of control suggested that the

training to do home hemodialysis was perceived as a situation which allowed the couple to have added control over their lives. In this study the joint partners perceived that dialysis gave them control; - control over when they did dialysis, control over their daily routines and independence from the hospital. This control allowed them to lead "normal" lives, including special events such as holidays. In contrast, the minimal assistants saw home hemodialysis as controlling their lives by the restrictions and changes imposed upon them by the treatment and the illness. The minimal assistants viewed home hemodialysis in direct opposition to them leading "normal" lives. The do-ers perceived that they were personally "controlled" by dialysis by virtue of their traditional and dialysis roles. However, do-ers did not perceive their lives as being so drastically altered as did the minimal assistants. The variations in the perceived nature of being "in control" or "controlled by" dialysis further differentiated these groups of spouses in a way consistent with the divisions based on level of involvement. The level of involvement may influence the amount of control these spouses perceive they have or they are subject to.

In summary, from the results in this study, the combination of two factors, level of involvement and level of resentment, describe most of the variability in the spousal experience with home hemodialysis. Three distinct groups of spouses emerged from

the data: the do-ers, the minimal assistants and the joint partners. Two broad themes relating to the marital relationship and the spouse's perceived degree of "normalcy" in their life also differentiated these spouses in to the same groups.

Chapter V: Conclusions and Recommendations

Study Limitations

Various limitations are present in this study. These are primarily due to the qualitative method of study and were largely unavoidable.

Chenitz and Swanson (1986) suggest that one of the potential drawbacks of Grounded Theory method is that the reactive effects of the researcher affect the data. The interview method used to collect data in this study was inherently interactive therefore the influence of the researcher could not be extracted from the method. However, in this study the interactive interview facilitated the spouses sharing many personal thoughts and experiences that were helpful to the researcher. In addition, the data analysis may have been analyzed differently by a different researcher. Chenitz and Swanson (1986, p.224) state that "[t]his is the principle limitation of qualitative research."

The objective of the study was to discover how the spouses experienced home hemodialysis. These perceptions are unique to the individual and cannot be ascertained from an interview with the partner. For this reason, the partners were not interviewed. The perspective of the patient is not the same as the perspective of the spouse helper.

During the interviews some of the information was recalled and some material was reflective. There may be problems with some

of the reflective data because ideas and feelings change over time.

This study was conducted over a period of four months. However, the spousal experience with home hemodialysis ranged from five months to eight years. Data collected from a particular point in time may not necessarily reflect changes over time although participants did reflect on their past experiences.

A further limitation of this study is that seven of the participants were female and one was male. The spousal perspective on assisting with home hemodialysis may be different for females and males but this could not be ascertained in this small sample.

Summary of Findings

Glaser (1978) states that the generation of Grounded Theory occurs around a core category which accounts for a major portion of variation in the observed behaviors. The core category in this study was "level of involvement." The level of involvement related to the amount of participation the spouse had in the home hemodialysis treatment. Spousal response to their level of involvement was reflected in their level of resentment towards living with a partner with ESRD and assisting with dialysis. Three clear types of spouses were identified from the varied spousal experiences. The do-ers had a high level of involvement and a high level of resentment. The do-ers essentially managed

the dialysis treatment for their partner. The minimal assistants had a low level of involvement with the dialysis treatment but had a high level of resentment towards dialysis because of the lifestyle changes it imposed. These spouses assisted very little, or not at all, with the dialysis treatment. The third group of spouses has been labelled the joint partners. These spouses had a relatively high level of involvement and a low level of resentment. These spousal pairs worked cooperatively on the dialysis treatment. The joint partners believed that home dialysis gave them, and their partners, control over their lives. The cooperative relationship between husband and wife gave these spouses a sense of being needed. This was in contrast to the do-ers who felt totally responsible and therefore burdened, and the minimal assistants who were marginally involved in the treatment and lacked a sense of commitment.

The results in this study support Brackney's (1977) findings that showed that the marital satisfaction of the spouse was positively related to adjustment to home hemodialysis. Analysis of the results shows that the pre-existing and ongoing marital relationship is a pervasive influence on the experience of the spouse in home hemodialysis. The findings in this study have extended the body of knowledge about spousal assistants for home hemodialysis patients. By getting the emic perspective of the spouse new information was gained. Whereas several authors

(Brackney, 1979; Conley et al., 1981; MacElveen, Hoover and Alexander, 1975; and Speidel, Koch, Balck, and Kniess, 1979) have studied the impact of home hemodialysis on spouses, it was done in association with patient partners therefore interaction was the focus of these studies and not specifically the individual spousal perceptions. In addition, all the studies listed above involved measurement of variables using specific instruments such as personality inventory tests, check-lists and rating scales. These instruments measured particular aspects chosen by the researcher. This study provided the opportunity for the assistant spouses to discuss what was important to them and therefore broadened the understanding of the perspective of a home hemodialysis spouse.

Dimond (1979, 1980) studied hemodialysis but focused on patient adaptation to managing maintenance hemodialysis. Spouses were studied only indirectly as an indication of social support. Spousal support was measured by a 10-item 5-point scale developed by the investigator. Data from these studies showed that spousal support of the patient partner contributed to successful management of home hemodialysis but it did not provide information about how this was experienced by the spouses themselves. Therefore, this study serves to extend other research by filling in gaps where there has been minimal research.

One study by Peterson (1985) studied women who assisted their husbands with home hemodialysis. Use of a staff rating scale and

an adapted version of the Sickness Impact Profile (SIP) were used to collect data about spousal adjustment to home hemodialysis. Weaknesses in the instruments, outlined by the researcher, have implications for the reliability and validity of the study. However, the results were a beginning effort to shed light on the experience of the spouses. This present study augments Peterson's study on the experience of the spouse who assists with home hemodialysis.

Nursing Implications

The results of this study have implications for nursing practice, administration and education. Home hemodialysis is a treatment that affects not only patients but spouses and other family members. The treatment involves highly technological skills that require training and experience to promote long term success. However, it is not only the treatment that affects spouses but the many lifestyle changes that must occur when living with a partner with ESRD. While the home hemodialysis partner is clearly the client for the hospital, nurses caring for the patient must be aware that home hemodialysis involves significant changes for the spouse. Results from this study show that home hemodialysis has a large impact on the lives of spouses. By being trained and acting as an assistant the spouse is implicated in a "chronic illness-way of life." Spouses should be given the opportunity, and encouraged, by nurses to explore their feelings.

Often the spouses themselves see their partner as the only patient and do not recognize their own needs. The spouses could benefit from help and support from nurses familiar with home hemodialysis.

Practicing nurses must be aware of, and sensitive to, potential risk factors in family dynamics that may create problems. Brackney (1977) suggests attending to the marital relationship and Conley (1981) recommends examination of communication between the spousal pair as well as support systems. The results from this study concur with the above authors that assessment of the spousal support system, communication and marital relationship are important variables in the whole experience of home hemodialysis.

This study offers insight into the perceptions of the spouse of a home hemodialysis partner. The spouses' problems and needs related to dialysis are different from those of the patient. For this reason it is important that the spouses be seen separately from their partner for ongoing support and assessment of their situation. Successful resolution of spousal problems with home hemodialysis will ultimately benefit the patient. Identification of problem areas is an important aspect of providing nursing care for these people. If the nurse is unable to resolve the problem, referral to another multi-disciplinary team member (i.e., a marriage counsellor) may be helpful.

This study also shows that spouses need a break from continuous home hemodialysis and could benefit from opportunities for respite. The restrictive nature of dialysis makes it difficult for these spouses to achieve time away from their situation. Some spouses could benefit from a total holiday from dialysis treatment. Treatments of their partner as an in-patient for a short period of time might be a good alternative. For some spouses, in-center dialysis treatment would not offer an acceptable alternative but a trained helper to assist in the home would be a viable option.

Nursing administration should support allocation of nursing resources for a thorough pre-training screening of prospective home hemodialysis spouses. Equally important is an ongoing assessment and evaluation of the effects of home hemodialysis on the spouse since many changes occur over time. When two persons are linked in a treatment as complex as home hemodialysis the needs of the assistant spouse should be as important as the needs of the patient partner. Finally, if nurses are to provide the assessment and support spouses require, the provision for continuing nursing education is important.

Nursing education must continue to emphasize the importance of the family. Wright and Leahey (1987, p.239) advise that "[w]hen dealing with persons with chronic illness, it is imperative that health professionals never lose sight of the fact

that the patient is the family." Promoting an understanding of not only the care of the patient but also the experience of living with chronic illness is important for nurses to provide appropriate care.

Directions for Future Research

This study is exploratory and was conducted to gain insight in to the experience of being the assistant spouse for a home hemodialysis partner. Data suggest that the spouse's level of involvement in the treatment is an important variable in the successful outcome of adapting to home hemodialysis. Specifically, the level of involvement is related to the level of resentment experienced by the spouse. The marital relationship also appears to be influential in how the couples manage lifestyle changes due to home hemodialysis and ESRD. It would be valuable to conduct empirical testing to measure these concepts and test their relationships. Hypothesis generated from this study include:

- Over and under-involvement by the spouse in the tasks required for home hemodialysis treatment are related to stronger feelings of resentment towards home hemodialysis than is cooperation between spouse and partner in dialysis-related tasks.

- Strong, cooperative relationships prior to initiation of home hemodialysis promote more successful adaptation to home hemodialysis than do unstable or strongly role differentiated relationships.

- Cooperative involvement in home hemodialysis results in increased satisfaction for spouses with self, with partner, with home hemodialysis and with life in general.

Results from this study support suggestions outlined by Brackney (1977) that examination of spousal relationships warrant further investigation. Examination of marital relationship as a possible predictor of success with home hemodialysis could provide information valuable for screening home hemodialysis candidates. From this study, important aspects of the relationship to investigate include spousal communication, role differentiation, task orientation, and mutual support between partners.

Other directions for future research could include investigation of the effects of children in the home and spousal employment outside the home as they affect, or are affected by, home hemodialysis. Studies similar to this one to examine chronic ambulatory peritoneal dialysis may provide useful information to caregivers and families involved with ESRD. Finally, longitudinal studies are required to follow spouses and their partners in order to distinguish between short and long term effects of home hemodialysis. This type of research is important so that adaptive changes, or lack of adaptation, can be more fully understood. It is hoped that the results of this study will stimulate further research of the management and adaptation to home hemodialysis patients and their families.

Conclusion

In this study the experience of being a spousal assistant for home hemodialysis was examined. The objective was to gain an understanding of how these people deal with a complex technological procedure at home and how they manage life with a partner who is chronically ill. Present knowledge was extended by investigating the concerns of spouses from the emic perspective. It was intended to be an exploratory descriptive study. Due to the limited number of spouses interviewed, results are not generalizable to all home hemodialysis spouses.

The use of Grounded Theory method (Glaser and Strauss, 1967) for data collection and analysis was a valuable method to answer the research questions. The "discovery" of the spouse's experience was facilitated. Strengths in the method of this study were promoted by the eagerness of the participants to willingly share their experiences with the researcher. Several factors helped to encourage participation in this study. Appropriate introduction of the researcher by a letter from the nephrologists, followed up by a telephone call by the researcher were important steps to gaining cooperation from the participants. In addition, scheduling of interviews at convenient times, in the participants' homes was noted to be helpful in permitting participation. Rapport between participants and the researcher was quickly established which contributed to rich data. From the data

concepts emerged and relationships between them became evident. A theory was developed relating the core variable, "level of involvement," with the level of resentment experienced by the spouses. As noted by Glaser (1978, p.93) "the goal of Grounded Theory is to generate a theory that accounts for a pattern of behavior which is relevant and problematic for those involved."

Ruffing-Rahal (1985) suggested that a critical task for health disciplines is to comprehend illness as a personal experience and long-term impairment as a way of life. This study contributes to the understanding of home hemodialysis and ESRD as a personal experience for the spouse who is inextricably involved in treating and living with a partner who has the chronic illness.

Bibliography

Bailey, G., Mocelin, A., Hampers, C.L., & Merrill, J.P. (1972). Home dialysis: 30,000 treatments later. Postgraduate Medicine, 52, 190-194.

Blagg, C.R., Hickman, R.O., Eschbach, J.W., & Scribner, B.H. (1970). Home hemodialysis: Six years' experience. New England Journal of Medicine, 283, 1126-1131.

Beard, B. H. (1969). Fear of death and fear of life. Archives of general psychiatry, 21, 373-380.

Bogdan, R.C., & Biklen, S.K. (1982). Qualitative research for education: An introduction to theory and methods. Boston: Allyn and Bacon.

Brackney, B.E. (1979). The impact of home hemodialysis on the marital dyad. Journal of Marital and Family Therapy, Jan. 55-60.

Bramwell, L. (1986). Wives' experiences in the support role after husbands' first myocardial infarction. Heart and Lung, 15(6), 578-584.

Brand, L., & Komorita, N.I. (1966). Adapting to long term dialysis. American Journal of Nursing, 66, 1778-1781.

Buchanan, D.C., & Abram, H.S. (1976). Psychological adaptation to hemodialysis. Dialysis and Transplantation, Feb., 40-42.

Buck, N., Roy, C., & Atcherson, E. (1986). Life with dialysis: Structured interviews provide feedback. Journal of Nephrology Nursing, 3(2), 78-81.

Chenitz, W.C., & Swanson, J.M. (1986). From practice to grounded theory. Menlo Park, CA: Addison-Wesley.

Conley, J.A., Burton, H.J., De-Nour, A.K., & Wells, G.A. (1981). Support systems for patients and spouses on home dialysis. International Journal of Family Psychiatry, 2(1-2), 45-54.

Craig, H.M., & Edwards, J.E. (1983). Adaptation in chronic illness: An eclectic model for nurses. Journal of Advanced Nursing, 8, 397-404.

Czaczkes, J.W., & De-Nour, K. (1978). Chronic hemodialysis as a way of life. New York: Brunner/Mazel, Pub.

D'Afflitti, J.G., & Swanson, D. (1975). Group sessions for the wives of home-hemodialysis patients. American Journal of Nursing, 75(4), 633-635.

Dickoff, J., & James, P. (1968). Researching research's role in theory development. Nursing Research, 17, 197-203.

Diers, D. (1979). Research in nursing practice. Philadelphia: J.B. Lippincott.

Dimond, M. (1979). Social support and adaptation to chronic illness: The case of maintenance hemodialysis. Research in Nursing and Health, 2, 101-108.

Dimond, M. (1980). Patient strategies for managing maintenance hemodialysis. Western Journal of Nursing Research, 2(3), 555-574.

Dimond, M., & Jones, S.L. (1983a). Chronic illness across the life span. Norwalk, CT: Appleton-Century-Crofts.

Dimond, M., & Jones, S. (1983b). Social support: A review and theoretical integration. In P.L. Chinn (Ed.), Advances in Nursing Theory Development. Rockville, MD: Aspen.

Eddins, B.R. (1985). Chronic self-destructiveness as manifested by noncompliance behavior in the hemodialysis patient. Journal of Nephrology Nursing, 2(4), 194-198.

Esmond, W.G., Strauch, M., Zapata, A., & Hernandez, F. (1967). Fourteen patient years experience with a simplified home-hospital chronic hemodialysis system. Transactions of American Society for Artificial Internal Organs, 13, 254-262.

Feldman, D.J. (1974). Chronic disabling illness: A holistic view. Journal of Chronic Diseases, 27, 287-291.

Field, P.A., & Morse, J.M. (1985). Nursing research: The application of qualitative approaches. London: Croome Helm Ltd.

Glaser, B.G., & Strauss, A.L. (1967). The discovery of grounded theory: Strategies for qualitative research. New York: Aldine Pub. Co.

Glaser, B.G. (1978). Theoretical sensitivity: Advances in the methodology of grounded theory. Mill Valley, CA: Sociology Press.

Hampers, C.L., & Merrill, J.P. (1966). Hemodialysis in the home - 13 months' experience. Annals of Internal Medicine, 64, 276-283.

Hampers, C., Schupak, E., Lowrie, E., & Lazarus, M. (1973). Long-term hemodialysis. (2nd Ed.) New York: Grune and Stratton.

Hansen, G.L. (1972). Caring for patients with chronic renal disease. Philadelphia: J.B. Lippincott.

Hart, M., Tanenbaum, F., & Thompson, A. (1985). Benefits derived from a multidisciplinary educational/support group. Journal of Nephrology Nursing, 2(4), 182-184.

Hilbert, G.A. (1985). An investigation of the relationship between social support and compliance of hemodialysis patients. American Nephrology Nurses Association Journal, 12(2), 133-136.

Hill, M. (1981). When the patient is the family. American Journal of Nursing, 81, 536-538.

Holcomb, J.L., & MacDonald, R. (1973). Social functioning of artificial kidney patients. Social Science and Medicine, 7, 109-119.

Jones, L.C., & Preuett, S.G. (1986). Self-care activities and processes used by hemodialysis patients. American Nephrology Nurses Association Journal, 13(2), 73-79.

Klein, R., Dean, A., & Bogdonoff, M. (1967). The impact of illness upon the spouse. Journal of Chronic Diseases, 20, 241-248.

Knafl, K.A., & Howard, M.J. (1984). Interpreting and reporting qualitative research. Research in Nursing and Health, 7, 17-24.

Kossoris, P. (1970). Family therapy - An adjunct to hemodialysis and transplantation. American Journal of Nursing, 8(70), 1730-1733.

Levy, N. (1974). Living or dying - Adaptation to hemodialysis (Ed.). Springfield, Ill: Charles C. Thomas.

Litman, T.J. (1974). The family as a basic unit in health and medical care: A social-behavioral overview. Social Science and Medicine, 8, 495-519.

Lowry, M.R., & Atcherson, E. (1980). Home dialysis dropouts. Journal of Psychosomatic Research, 24, 173-178.

MacElveen, P.M. (1972). Cooperative triad in home dialysis care and patient outcomes. In M.V. Batey (Ed.) Communicating nursing research - The many sources of nursing knowledge, Volume 5, 134-147. Boulder, Co: Western Interstate Commission for Higher Education.

MacElveen, P.M., Hoover, P.M., & Alexander, R.A. (1975). Patient outcome success related to cooperation among patient, partner and physician. Journal of American Association of Nephrology Nurses and Technicians, 2(4), 148-155.

McKee, D.C. (1977). Effects of hemodialysis and home dialysis training on kidney patients and their spouses. Dissertation Abstracts International, 37(8-B), 4155.

Mead, M. (1976). Towards a human science. Science, 191, 903-909.

Moos, R.H. (1984). Coping with physical illness - New perspectives (Ed.). New York: Plenum Medical Book Co.

Morse, J.M. (1986). Quantitative and qualitative research: Issues in sampling. In P. Chinn (Ed.), Methodological issues in nursing. Maryland: Aspen Press.

Norbeck, J.S. (1981). Social support: A model for clinical research and application. Advances in Nursing Science, July, 43-59.

O'Brien, M.E., Donley, R., Flaherty, M.J., & Johnstone, B. (1986). Therapeutic options in end-stage renal disease: A preliminary report. American Nephrology Nurses Association Journal, 13(6), 313-318.

Palmer, S.E., Canzona, L., & Wai, L. (1984). Helping families respond effectively to chronic illness - Home dialysis as a case example. In R.H. Moos (Ed.), Coping with physical - New perspectives, 283-294. New York: Plenum Medical Book Co.

Peterson, K.J. (1985). Psychosocial adjustment of the family caregiver: Home hemodialysis as an example. Social Work in Health Care, 10(3), 15-32.

Plough, A.L. (1986). Borrowed time. Philadelphia: Temple University Press.

Rapaport, F. (1973). A second look at life. New York: Grune and Stratton.

Reichardt, C.S., & Cook, T.D. (1979). Qualitative and quantitative methods in evaluation Research (Ed.). Beverly Hills: Sage Publications.

Reichsman, F., & Levy, N.B. (1972). Problems in adaptation to maintenance hemodialysis. Archives of Internal Medicine, 30, 859-865.

Richard, C.J. (1986). Comprehensive nephrology nursing. Boston: Little, Brown and Co.

Rosser, R.M. (1982) Life with artificial organs: Renal dialysis and transplantation. In E. Shepherd & J. Watson (Eds.). Personal meanings, 159-174. New York: John Wiley & Sons.

Ruffing-Rahal, M.A. (1985). Well-being and chronicity: Being singular rather than sick. Health Values, 9(5), 17-22.

Schoeneman, S.Z., & Reznikoff, M. (1983). Personality variables in coping with the stress of a spouse's chronic illness. Journal of Clinical Psychology, 39(3), 430-436.

Schreiber, W., & Huber, W. (1985). Psychological situation of dialysis patients and their families. Dialysis and Transplantation, 14(12), 696-698.

Sexton, D.L., & Munro, B.H. (1985). Impact of a husband's chronic illness (COPD) on the spouse's life. Research in Nursing and Health, 8, 83-90.

Shambaugh, P., Hampers, C. Bailey, G., Snyder, H., & Merrill, J. (1967). Hemodialysis in the home - Emotional impact on the spouse. Transactions of American Society of Artificial Internal Organs, 13, 41-45.

Shambaugh, P., & Kanter, S. (1969). Spouses under stress: Group meetings with spouses of patients on hemodialysis. American Journal of Psychiatry, 125(7), 100-108.

Smith, E.K., Curtis, J.R., McDonald, S.J., & DeWardener, H.E. (1969). Hemodialysis in the home - Problems and frustrations. The Lancet, 1, 614-617.

Speidel, H., Koch, U., Balck, F., & Kniess, J. (1979). Problems in interaction between patients undergoing long-term hemodialysis and their partners. Psychotherapy, 31, 235-242.

Srivastava, R.H. (1987). Conscious coping strategies used by spouses of patients on continuous ambulatory peritoneal dialysis. Paper presented to University of Alberta Hospitals Nursing Research Conference, May 28.

Stapleton, S. (1983). Recognizing powerlessness: Causes and indicators in patients with chronic renal failure. In J. F. Miller (Ed.), Coping with chronic illness, 135-148. Philadelphia: F.A. Davis.

Stark, C.R. (1985). Home and in-center hemodialysis patients - A descriptive study. Journal of Nephrology Nursing, 2(2), 77-79.

Steidl, J.H., Finkelstein, F.O., Wexler, J.P., Feigenbaum, H., Kitsen, J., Kliger, A., Quinlan, D. (1980). Medical condition, adherence to treatment regimens and family functioning in patients receiving long-term dialysis. Archives of General Psychiatry, 37, 1025-1027.

Strauss, A.L. (1975). Chronic illness and the quality of life. Saint Louis: C.V. Mosby.

Strauss, A.L. (1986). Research on chronic illness and its management (The Fifth Helen Nahm Research Lecture, School of Nursing, University of California, San Francisco).

Streltzer, J., Finkelstein, F., Feigenbaum, H., Kitsen, J., & Cohn, G.L. (1976). The spouse's role in home hemodialysis. Archives of General Psychiatry, 33, 55-58.

Walker, A.J. (1985). Reconceptualizing family stress. Journal of Marriage and The Family, Nov., 827-837.

Walters, D. (1985). Dialogue on coping. The Renal Family, 7, 5.

Waltz, M. (1986). Marital context and post-infarction quality of life: Is it social support or something more? Social Science and Medicine, 22(8), 791-805.

Wright, L.M., & Leahey, M. (1987). Families & chronic illness. Springhouse, PA: Springhouse.

Appendix A

Informed Consent Form

APPENDIX A

UNIVERSITY OF ALBERTA FACULTY OF NURSING
INFORMED CONSENT FORM

Project Title: Home Hemodialysis: The Experience of the Spouse as the Designated Helper.

Investigator: Dawn Friesen
Faculty of Nursing, Graduate Education Office
Clinical Sciences Building, University of Alberta
Edmonton, Alberta. T6G 2G3
Home Phone Number: 437-6789

Purpose of the Study: The purpose of this study is to investigate the experience of spouses who are "designated helpers" for home hemodialysis patients. It is anticipated that the results of this study will provide health care workers with a better understanding of how spouses adapt to management of hemodialysis in the home setting. The information and understanding gained should help health care workers more effectively prepare both patients and their spouses for home hemodialysis and to provide ongoing assistance.

Risks and Benefits: There are no known risks associated with participation in this study. There may be no direct benefits to the participants however, future home hemodialysis patients and their spouses may receive more effective care based on the results of this study.

Consent: This is to certify that I, _____, consent to participate in the research study outlined above. I hereby give permission to be interviewed for approximately one hour, three to four times by D. Friesen in my home, over a period of approximately two months. I understand that each interview will be tape recorded and that these tapes will be stored in a locked file for five years and then destroyed. I understand that upon completion of the study, findings may be published but that my personal identity and characteristics will be protected.

I understand that I can terminate any interview at any time, refuse to discuss any subject I wish not to discuss, or withdraw from the study, with no consequence.

I have been given an opportunity to ask the investigator any questions I have concerning the study. The investigator, D. Friesen, has answered any questions to my satisfaction.

DATE: _____ SIGNATURE: _____

INVESTIGATOR: _____ WITNESS: _____